MEDICAID HOME CARE OPTIONS FOR DISABLED CHILDREN

NATIONAL GOVERNORS' ASSOCIATION

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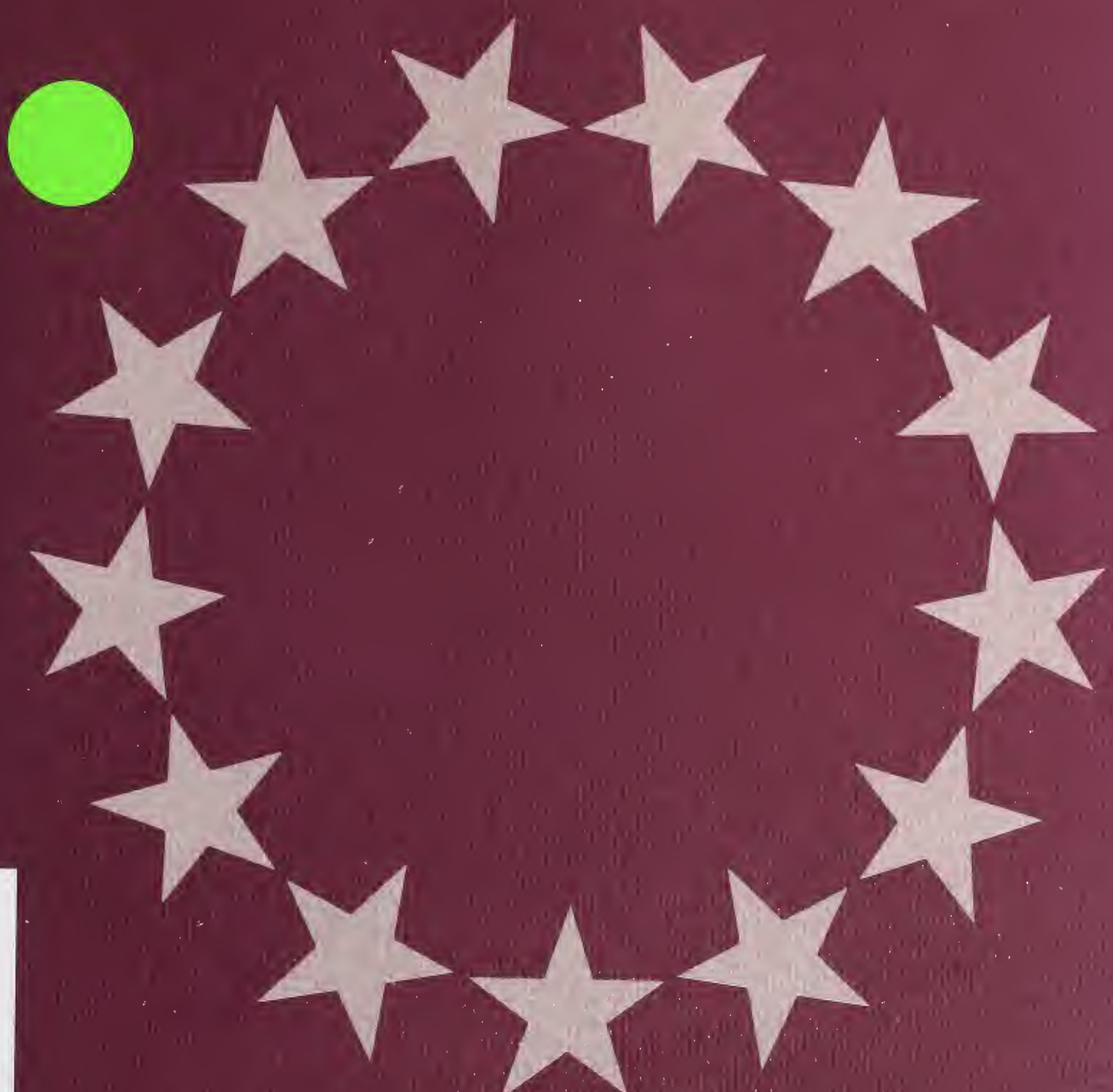
State Medicaid Issues



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population and of the issues surrounding their health care portend increasing complexities in providing them quality, community-based care. Growing numbers of disabled children, identifying appropriate alternative care settings, finding providers to care for such children, and deciding the public and private sector financial roles in supporting their care are just a few of the issues in development.

The National Governors' Association is pleased to provide you with this complementary copy of our report on these issues and states' successful use of Medicaid options to provide quality, community-based care for disabled children. For further information on the report, please feel free to call Linda Hall at (202) 624-7729.

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January 17, 1990

TO: Interested Parties

FROM: John Luehrs, Director
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RE: MEDICAID HOME CARE OPTIONS FOR DISABLED CHILDREN

Nationwide, children with severe chronic physical or mental illnesses number about 2 million. Of these, approximately 500,000 are impaired so severely that they are unable to participate in major life activities, which for young children generally includes attending school. Chronically ill children are intensive users of health care services and, on average, their annual health care costs are three times those of healthy children.

Medicaid, the primary public payor of health care for severely chronically ill children, has two primary options through which community-based care can be provided: home- and community-based waivers, which were authorized under the Omnibus Budget and Reconciliation Act of 1981, and a state plan option for disabled children under age eighteen, which was authorized under Section 134 of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA).

The attached special report, Medicaid Home Care Options for Disabled Children, analyzes states' use of these options to coordinate medical and support services to children living at home. It was prepared by Linda Hall under National Governors' Association's contract with the Health Care Financing Administration's Intergovernmental Affairs Office to operate the State Medicaid Information Center.

Thirty-six states, operating a total of sixty-six home- and community-based services (HCBS) waivers, are avoiding some of the high costs of institutional care while providing disabled children appropriate care and specialized services in a home or community setting. For seventeen states, the TEFRA state plan option offers another avenue for delivering cost-effective home care to recipients. While it has broader income eligibility criteria, this option differs from the HCBS waiver program in that only services regularly available under the state's Medicaid program are covered.

The TEFRA and HCBS waivers options share many planning and implementation challenges. Although the current challenges in caring for disabled children are substantial, the evolving nature of the

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State Medicaid Issues

by Linda Hall

Health Policy Department
Human Resources Policy Studies Division
Center for Policy Research

National Governors' Association

The National Governors' Association, founded in 1908 as the National Governors' Conference, is the instrument through which the nation's Governors collectively influence the development and implementation of national policy and apply creative leadership to state issues. The association's members are the Governors of the fifty states, the commonwealths of the Northern Mariana Islands and Puerto Rico, and the territories of American Samoa, Guam, and the Virgin Islands. The association has seven standing committees on major issues: Agriculture and Rural Development; Economic Development and Technological Innovation; Energy and Environment; Human Resources; International Trade and Foreign Relations; Justice and Public Safety; and Transportation, Commerce, and Communications. Subcommittees and task forces that focus on principal concerns of the Governors operate within this framework.

The association works closely with the administration and Congress on state-federal policy issues through its offices in the Hall of the States in Washington, D.C. The association serves as a vehicle for sharing knowledge of innovative programs among the states and provides technical assistance and consultant services to Governors on a wide range of management and policy issues.

The Center for Policy Research is the research and development arm of NGA. The center is a vehicle for sharing knowledge about innovative state activities, exploring the impact of federal initiatives on state government, and providing technical assistance to states. The center works in a number of policy fields, including agriculture, economic development, education, environment, health, social services, training and employment, trade, and transportation.

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Executive Summary

Nationwide, children with severe chronic physical or mental illnesses number about 2 million. Of these, approximately 500,000 are impaired so severely that they are unable to participate in major life activities, which for young children generally includes attending school. Chronically ill children are intensive users of health care services and, on average, their annual health care costs are three times those of healthy children.

In the early 1980s, federal and state policymakers began to focus on the problem that existing health care systems and funding for the chronically ill were neither adequately supporting children and their families nor maximizing the use of the home and other care settings. The negative effects of long-term hospitalization on children's growth and development were recognized, and advanced medical technology made care outside hospitals and nursing homes safe and feasible. However, public financing programs inhibited the movement of children to community-based, less costly settings.

Options for Home Care

Medicaid, the primary public payor of health care, could assist all chronically ill who met its income and eligibility guidelines. However, services available in the community often were inadequate to meet the needs of severely chronically ill children. In the institution, Medicaid could cover all necessary services, but provided them in a restrictive and expensive setting. Some institutionalized children could be cared for appropriately at home but income guidelines and rules for the noninstitutionalized made it difficult to support them at home, even when home care would cost Medicaid less than institutional care.

In response to these limitations, numerous legislative and administrative policy changes were adopted during the 1980s to increase opportunities for family-centered, community-based care. These changes patterned the development of the two primary Medicaid community-based care options: home- and community-based waivers, which were authorized under the Omnibus Budget and Reconciliation Act of 1981, and a state plan option for disabled children under age eighteen, which was authorized under Section 134 of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA). Through these programs states coordinate medical and support services to children living at home and avoid costly institutional payments for their care. Although all states continue to serve institutionalized children and those who meet the standard income guidelines, most states also take advantage of the broader eligibility criteria and increased services available under these options.

Home- and community-based services (HCBS) waivers offer important avenues for Medicaid to avoid some of the high costs of institutional care while providing individuals appropriate care in a home or community setting. Waivers also afford the opportunity to offer specialized services to target groups. These services may include expanded medical services and other support services such as habilitation and respite care, which are not normally covered by Medicaid. Because states often elect to use more expansive income eligibility criteria when they develop waivers, more disabled children can access such waivers and benefit from their specialized services.

Responses to the National Governors' Association's Survey on Medicaid Home Care Options for Disabled Children and the Health Care Financing Administration's September 1989 list of approved waivers indicate that 52 percent of all waivers include children. Currently, thirty-six states operate a total of sixty-six waivers that include children. Forty-two are regular waivers and twenty-four are model waivers. Because waiver data are not age-specific, it is difficult to determine exactly how many children are served under these sixty-six waivers. However, it is clear that waivers are widely used to meet the special care requirements of disabled children.

The TEFRA state plan option offers another avenue for providing cost-effective home care to recipients. While it has broader income eligibility criteria, only services regularly available under the state's Medicaid program are covered under this option. The eligibility criteria allow coverage of all disabled children under age eighteen who require institutional care, but who can be cared for appropriately and cost-effectively at home. Essentially, this option allows states to extend regular Medicaid to children who would be eligible if they were in an institution. Seventeen states have selected the TEFRA option.

State Experiences in Home Care

The TEFRA and HCBS waivers options share many planning, implementation, and analysis challenges. For both options, states must consider numerous issues, including eligibility expansions, care coordination, provider availability and reimbursement, case review, program administration, and cost. How states evaluate each of these factors varies depending on their Medicaid program and disabled population. States' conclusions on these issues inform their decisions as to the best strategy for serving disabled children in the community.

State experience demonstrates that each option has advantages and that there are good reasons for maintaining both. The TEFRA program covers more disabled children, while the waiver program affords states the opportunity to target categories of individuals and to develop innovative care programs suited to their specific needs. States may use one option or both in developing a strategy for serving disabled children in the community.

While both options offer expanded opportunities for community care as well as effective management of Medicaid costs, their underlying cost-effectiveness principles present eligibility and service problems for some disabled children. Under both programs, Medicaid covers children whose community-based health care costs the

same or less than what Medicaid would pay for such children's institutional care. Thus, Medicaid compares its share of the institutional cost—not total institutional cost—to its share of the home care cost. This principle constrains eligibility for some children and limits services for others who do qualify.

Some children who could be cared for at home cannot qualify because their home care would cost Medicaid more than it spends on their institutional care. While such obstacles can be present for many children, they most frequently occur for children who have private insurance covering institutional care but not home care. If private insurance covers the entire costs for institutional care or if it pays an amount that is equal to or more than the Medicaid limit, there is no Medicaid payment. If Medicaid pays nothing for the institutional care, then even one Medicaid dollar spent on home care causes the child to fail the cost-effectiveness test. In such cases, under current rules, Medicaid avoids those costs by leaving the child in the hospital.

Cost containment principles also can constrain services to children who do qualify for home care, because their home care cannot exceed comparable institutional costs. Where needs exceed private insurance and Medicaid coverage, alternative payment and service delivery sources must be specified. For example, hourly nursing care above the Medicaid limits may be essential. If Medicaid cannot pay for those hours, perhaps another program can offer support. However, if no other sources can be identified, the child may have to remain in the institution or the family may be asked to cover more hours. Once again, cost containment can constrain the process of planning comprehensive, quality home health care.

Upon development of the plan of care, states, providers, and disabled children and their families must work together to achieve its successful implementation. State experience demonstrates that care coordination is important to the success of home care programs for disabled children. Care coordinators monitor all aspects of a child's home care program. They review the plan elements, consider changes to the plan when the child's health status changes, assist in identifying new providers when there are shortages of providers or problems with them, access services from other state agencies, and sometimes review claims for consistency with care plan requirements. A care coordinator who knows the child, the family, available community providers, and the state agency network can make the difference in the effectiveness of a home care plan.

Some private insurers pay for some home health services, primarily skilled nursing and medical supplies. Where privately funded home health benefits exist, states utilize them in developing home care packages and work with insurers to increase their support of the home as a care option. Massachusetts, Rhode Island, and Vermont are among the states working with insurance companies to encourage their conversion of hospital benefits to home health benefits for Medicaid recipients. Minnesota developed an interdisciplinary panel that serves as an intermediary for technology-dependent individuals who are in dispute with their private insurance companies over home health benefits. The state expects this panel's intervention to delay or prevent Medicaid applications. Although private insurers are considering home health more seriously for their high-cost cases, continued effort is needed before the commitment of the private sector equals that of the public sector.

While delineating necessary services and identifying payment sources present significant obstacles to successful care plan implementation, there are other difficulties. For care coordinators and families, shortages of physicians, nurses, therapists, and home health aides appropriately trained and willing to work with disabled children present additional challenges. When providers are unavailable, families inevitably are the backup. High turnover means additional work for the family in acquainting new nurses with their child and in communicating their expectations of how the nurse/family relationship should proceed. One response to provider shortages is increased reimbursement to home health providers. However, higher home health rates may lead to more difficulty in justifying the cost-effectiveness of many home care cases. Although Medicaid reimbursement rates are an important issue vis-a-vis provider supply, so are recruitment, training, and certification. Arkansas and Maryland are among the states experimenting with recruitment and training programs to improve provider supply.

Adequate numbers of providers and consistent, coordinated care are critical to families, but so are psychosocial services and respite care. These families must pay the extraordinary medical, social, psychological, and financial costs associated with their children's intensive health care needs. Families who care for disabled children report increased family stress, lost income due to increased caregiving hours and reduced employment hours, lost career opportunities, and less time to spend with other family members. Many states report that families receiving adequate medical and support services are better able to maintain their commitment to home care for their children, thus delaying or avoiding costly institutionalizations often paid for by Medicaid.

Future Considerations in Home Care

The current challenges in caring for disabled children are substantial. Yet, the evolving nature of the population and of the issues surrounding their health care portend increasing complexities in providing them quality, community-based care. Growing numbers of disabled children, finding providers to care for such children, and deciding who should pay for their care are just a few of the myriad dilemmas.

As increasing numbers of health-compromised children survive, decisions on what constitutes an adequate quality of life will need to be addressed even as medical technology is available to support the continuation of life. Part of this decisionmaking will need to weigh the public and private sectors' willingness to support families' caring for disabled children.

Another issue in community-based care for these children is the range of alternatives to institutional care. Efforts to move children out of institutions and into the community must not presume that every family is capable of caring for their child. Some families cannot meet the home care challenge or sustain its demands over a disabled child's lifetime. For children whose families cannot care for them, for those whose families require respite from care demands, and for older children requiring independent living situations, alternative community-based settings are needed. Presently, there are few alternatives to the institutional or home setting. Developing

a range of community, home-like settings is important to the future of continuous community-based care for disabled children.

In addition to developing alternative settings, further delineation of the public and private sector roles in financing community service systems will be important. Currently, the public sector has the lead in coordinating and paying for home care. While agencies funded through federal and state dollars participate in such efforts, Medicaid is the primary public funding source for home care. However, it can participate only to the extent that home care costs are less than institutional care. This cost containment restraint has a significant impact on the shape of current home care programs. Furthermore, for Medicaid, funding of home care raises issues about allocating dollars among healthy and disabled children.

The question of how to spend public dollars is intimately related to how private health care dollars are being used. While some private insurers already are covering some costs for these children, most private insurers remain reluctant to provide comprehensive home health coverage for disabled children. Their plans contain biases for institutional care and against home care. When plans do cover home health, they often are limited to higher-cost services and providers, which encourage more rapid spenddown of total benefit dollars. Whether through paying for high-cost home health services or institutional care, the $1 million benefit cap on most insurance plans is easily exhausted by disabled children.

Another financial role to be considered in payment of home care is that of contribution by the family. Is a policy requiring families to contribute toward the substantial costs of home care reasonable, or will it foster negative incentives encouraging them to place their children in institutions or medical foster care?

Private and public roles in financing home care must be considered together in order to develop consistent policy with appropriate incentives for private insurers, families, and public agencies to support efficient, comprehensive home care for disabled children. How policymakers resolve these issues will influence the further development and structure of community-based care programs. State Medicaid agencies' experience in this arena and their role as the primary public payors of care for these children should guarantee them a central role in the continuing debate.

Although many issues surrounding community-based health care for disabled children continue to evolve and present care coordination challenges, states are successfully using existing home care program options to provide medical and support services to children living in the community. To develop such programs, Medicaid and related state agencies coordinate for efficient use of all available expertise and fiscal resources. Through such efforts states continue to lead in the design and implementation of quality community-centered care for disabled children.

1. Disabled Children: Population and Programs

Population Characteristics

Chronically ill children are those suffering a chronic condition or illness that lasts for a substantial period of time and has continuing or debilitating effects. The illnesses afflicting children are wide-ranging and include cystic fibrosis, cerebral palsy, muscular dystrophy, Down syndrome, congenital heart disease, asthma, bronchopulmonary dysplasia, short bowel syndrome, leukemia, seizure disorders, traumatic brain injury, blindness, renal failure, and AIDS. Chronic illnesses often contribute to mental retardation or developmental disability or delay.

Seventeen million children have some type of chronic physical or mental condition. Of these, 2 million are considered severely chronically ill. Approximately 1 million are restricted in their ability to participate in some fundamental life activities such as school or appropriate play for preschool-age children.

Approximately 150,000 of the 2 million severely chronically ill children experience restrictions in all major life activities (Newacheck 1987). A subset of this group are technology-dependent children who number between 2,300 and 15,000. These children require ventilator assistance, parenteral nutrition, intravenous drugs, or other device-based respiratory or nutritional supports (Office of Technology Assessment 1987).

Chronically ill children are growing both in absolute numbers and in proportion to the number of healthy children. Data from the National Health Interview Survey indicate that between 1960 and 1984, the number of chronically ill children rose from 2 percent to 5 percent of children under age seventeen (Newacheck 1987). The major factor contributing to the increased numbers during these years probably was advancement in medical technology. Advanced medical technology contributes to the survival of more premature, partially developed, and low-birthweight babies. It also contributes to longer lives for children who survive prematurity, low birthweight, and severe chronic illness.

Since 1984, the greater incidence of drug and alcohol addiction among pregnant women, together with continued medical advancements, may have further increased the number of chronically ill children by fostering the survival of addicted infants with numerous mental and physical problems. The number of impaired infants may increase still further as the number of babies born with Human Immunodeficiency Virus (HIV) infection increases. While these babies sometimes are healthy at birth,

their lives can be expected to be short and characterized by severely compromised health.

Perhaps contributing to even greater numbers of chronically ill children, too, is the fact that one in five American children lives in poverty. Disability appears to be more prevalent among poor children (Congressional Research Service 1988). If this theory is true, the rise in poverty over the past decade must have added to the count of chronically ill and disabled children. Although the precise increase in the number of chronically ill children is unknown, available data and observations of infants' health over the past few years certainly suggest it has been significant. Moreover, the increase is likely to continue as long as chemical addiction and HIV-infection occur frequently among childbearing women.

Health Care Services and Costs

Severely chronically ill and disabled children are intensive users of health care services. Compared with healthy children, they use two times as many basic health services; two times the number of physician visits; twice as many prescribed medications; four times the number of allied health professional services; and six times the number of physical therapy, respiratory therapy, social work, and psychological services. Data are not available on use of durable medical equipment and supplies, special supplies for institutionalized children, and home renovations for community-based children. If such data were available, the differentials in resource usage would be even more dramatic (Newacheck 1987).

Despite incomplete medical supply cost data, differences in health care expenditures for a healthy child and for a disabled child are significant. Based on data from the 1980 National Medical Care Utilization and Expenditures (NMCUE) Survey, average inflation-adjusted health care costs for a healthy child are $430 per year. Disabled children average three times that amount, or $1,242 per year (Newacheck 1987). However, averages are misleading, and the costs to care for some disabled children can reach thousands of dollars per month and tens of thousands per year. Indeed, the NMCUE Survey indicates that 65 percent of the health care costs are expended on the upper 10 percent of disabled children, and 87 percent on the highest quartile.

The substantial health care costs for disabled children are paid for through some combination of private insurance, family out-of-pocket expenditures, and public dollars. Based on NMCUE Survey data, 75 percent of all disabled children had access to private insurance. Some 500,000 disabled children had insurance coverage for a portion of the year, but 200,000 had none (Newacheck 1987).

Family out-of-pocket expenditures generally supplement private insurance. Data suggest that as many as 500,000 families spent more than $1,500 out-of-pocket in 1987. Approximately 255,000 families spent 20 percent of their annual income on their children's health care costs (Rymer and Burwell 1989).

Public sources of support for these children include the following: Medicaid, Children with Special Health Needs Program (formerly known as Crippled Children's Services), Assistance for Education of All Handicapped Children, Handicapped

Infants and Toddlers Program, Maternal and Child Health (MCH) Block Grants, Developmental Disabilities Basic State Grants Program, state- or county-funded programs for the medically indigent, and uncompensated care. Of these sources, Medicaid is the primary payer of health care services. The Children with Special Health Needs Program (CSHN) assists a small percentage of families, but focuses its efforts on structuring and improving the efficiency of family-centered, community-based care systems. Funds for handicapped children pay for educational needs and for coordination of federal, state, and local efforts on behalf of these children. MCH and Developmental Disabilities Grants are used by states in creating other support programs, while state- and county-funded medically indigent programs pay for medical services not covered by federally funded programs. Finally, uncompensated care in hospitals, clinics, and providers' offices cover some medical needs of individuals known to them.

The patchwork of public and private funds creates a challenging maze for state agencies and families attempting to address the health care needs of disabled children. Often the care plan for a single child requires support from all funding sources and programs.

Medicaid and Disabled Children

Medicaid is a federally and state-funded program that pays for medical services to certain groups of low-income persons. States have considerable flexibility to design and administer their own program within broad federal guidelines. State programs vary in terms of eligibility standards, service coverages, and reimbursement rates. The standards developed by a state are documented in its Medicaid state plan. Persons meeting the state's eligibility, income, and resource standards are entitled to Medicaid payment for covered, medically necessary services furnished by qualified providers. In fiscal 1987, Medicaid covered 23 million individuals nationwide and paid for medical services totaling $49 billion. States paid about 44 percent of those costs, and the federal government approximately 56 percent through matching payments to states.

Although states have latitude to select eligibility groups, the definition of the subset of chronically ill children covered by Medicaid home care programs is generally governed by the federal Supplemental Security Income (SSI) program's disability standard. Children are considered disabled if they suffer from an impairment that would qualify an individual over age eighteen as disabled. The SSI definition of a disabled adult is one who is unable to be substantially gainfully employed due to any medically determinable physical or mental impairment that can be expected to result in death or that can be expected to last for a continuous period of twelve months. For children, the degree of disability is measured by using functional assessments of developmental delay and limitations in major activities of daily living, which include performing age-appropriate activities, and where applicable, attending school. According to the Social Security Administration, there are 300,000 children nationwide who have applied for SSI and satisfied its disability definition.

In addition to meeting the disability criterion, children must meet SSI income and resource standards in order to qualify for Medicaid coverage. In 1989, an SSI

recipient was allowed to have income of up to $368 per month and resources of up to $2,000. Meeting these standards is easy for most institutionalized and foster children since only their income and resources are considered and usually they have none. However, children living with their family have more difficulty meeting the standards, since their entire family's income and resources must be considered.

For this reason, federal policy was changed to allow children to qualify for SSI based on their own income through the "waiving" of rules that require counting parental income and resources when the child lives at home. This process, called "the waiver of income deeming," allows SSI disabled children from middle- or even upper-income families to qualify for Medicaid coverage at home. Higher-income families can bring their disabled children home from institutions, and Medicaid can assist in paying for home health care while avoiding expensive institutional reimbursements.

This policy change resulted from increased awareness in the early 1980s that existing care systems and funding for chronically ill and disabled children were neither adequately supporting children or their families nor maximizing the use of home and other treatment settings. The negative effects of long-term hospitalization on children's growth and development were recognized, and advanced medical technology made care outside hospitals and institutions safe and feasible. However, public financing programs inhibited the movement of children to community-based, less costly settings.

Over the last decade, numerous legislative and administrative policy changes were adopted to increase opportunities for family-centered, community-based care. These changes patterned the development of the two primary Medicaid community-based care options: Home- and Community-Based Services (HCBS) waivers and the TEFRA state plan option. They also influenced related services used by Medicaid to support these program options.

Home Care Options History

The first legislative action vis-a-vis the development of HCBS waivers occurred in 1981, when Congress authorized Medicaid coverage of medical and support services to individuals in the community through home- and community-based waivers. Section 1915(c) of the Social Security Act, created by Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (OBRA 81), allows states to use "2176 waivers" for services to individuals, who without such services, require or are at risk of institutionalization. Their hospital, skilled nursing, or intermediate level of care at home must be no more expensive than it would be in an equivalent institutional setting.

Under 2176 waivers, states can fashion home care programs that include medical services not covered under the state plan as well as case management, respite care, home modifications, and transportation services otherwise not permitted under Medicaid. A state's waiver application must include the types of services to be offered and the number of individuals to be served. Waivers may target specific geographic areas within the state and/or categories of recipients such as aged/disabled, mentally retarded, mentally ill, or disabled children.

Chronology of Medicaid Home Care Options

1981 Home- and Community-Based Services (HCBS) waivers are authorized under Section 1915(c) of the Social Security Act via Section 2176 of reconciliation legislation. Called "2176 waivers," HCBS waivers offer Medicaid agencies new avenues to respond to recipients' long-term care needs through targeted, specialized community-based services (P.L. 97-35, Omnibus Budget and Reconciliation Act of 1981, Section 2176).

In Iowa, ventilator-dependent Katie Beckett cannot come home from the hospital because her Medicaid coverage would stop if she left the hospital, and her parents cannot afford to pay for her total care. The President authorizes her Medicaid coverage, creating the first "Katie Beckett" waiver. A Department of Health and Human Services review board is established to render case-by-case decisions on waiver of income deeming rules.

1982 The disabled children home care state plan option is enacted. States may waive income deeming rules for disabled children under age eighteen who meet an institutional level of care need and can be cared for cost-effectively at home under regular Medicaid services (P.L. 97-248, Tax Equity and Fiscal Responsibility Act of 1982, Section 134).

The Health Care Financing Administration develops application procedures for HCBS "model" waivers. Model waivers waive the income deeming rules. Limited to fifty persons, these waivers receive priority treatment in the application review process.

1985 Targeted case management as a state plan option is authorized. States can select target groups and offer them assistance in accessing medical and support services. Previously, states could manage recipients' care through administrative methods or could provide case management services through waivers (P.L. 99-272, Consolidated Omnibus Budget Reconciliation Act of 1985).

1986 Free and appropriate public education to children with disabilities between the ages of three and five is required by school year 1991-92. Such requirements already applied to older children. Amendments also allow states to establish comprehensive early intervention programs for developmentally delayed infants and toddlers up to age three (P.L. 99-457, Amendments to the Education for the Handicapped Act).

Congressional concern over AIDS leads to authority for states to establish "illness specific" waivers. Any particular illness or condition may be designated by the waiver (P.L. 99-509, Omnibus Budget Reconciliation Act of 1986).

1987 Building upon earlier amendments, Congress authorizes coverage of ventilator-dependent individuals who may be served cost-effectively at home (P.L. 100-203, Omnibus Budget Reconciliation Act of 1987).

1988 The model waiver limit of fifty persons is increased to 200 persons. States may limit model waivers to under 200 (P.L. 100-360, Medicare Catastrophic Coverage Act of 1988).

Waiver applications are submitted for a three-year period and may be renewed for either a three-year or five-year period. For waivers to be approved by the Health Care Financing Administration (HCFA), states must assure that:

> The agency's actual total expenditures for home- and community-based and other Medicaid services provided to individuals under the waiver will not, in any year of the waiver period, exceed the amount that would be incurred by Medicaid for these individuals in a hospital, skilled nursing facility, intermediate care facility, or intermediate care facility for the mentally retarded, in the absence of a waiver (Health Care Financing Administration 1989).

HCFA specifies the formula to calculate cost-effectiveness (see Appendix A). At the end of each waiver year, a state must submit cost reports and verify that the cost-effectiveness criterion was met for the group.

Another variation of the 2176 waiver was established in 1982, when HCFA established application procedures for "model" waivers. Model waivers follow the 2176 guidelines but the application requires less information. Limited to smaller populations, these waivers are given priority and are usually approved more quickly than are regular waivers. Originally, HCFA required a fifty-person limit in model waivers, but an amendment to Section 1915(c), contained in the Medicare Catastrophic Coverage Act of 1988, prohibits HCFA from imposing a limit of fewer than 200 persons.

"Katie Beckett" waivers for individual children also were established in 1981, but through administrative action. A ventilator-dependent child, Katie Beckett, was unable to leave a hospital because when she went home her parents' income would have been considered available to her and she would lose her Medicaid eligibility. The President responded to Katie Beckett's situation by authorizing her Medicaid coverage, creating the first "Katie Beckett" waiver. Subsequently, a Department of Health and Human Services review board was established to render case-by-case decisions on waiver of income deeming rules. This new authority helped many children leave institutions and return home. Although new individual waivers are no longer granted, children are still being served under existing waivers.

Federal policy broadening the authority granted under the Katie Beckett waiver was established under Section 134 of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), known in Medicaid as the TEFRA state plan option. The TEFRA option in Section 1902(e)(3) of the Social Security Act allows states to serve disabled children at home with regular state plan services if they would be eligible in an institution yet can be cared for appropriately and cost-effectively at home. Initially, only children receiving SSI were eligible under this option, but a technical amendment in 1988 modified the law to include any Medicaid-eligible disabled child who needs an institutional level of care. This modification expanded eligibility to children in states not already extending Medicaid to SSI children.

Another state plan option, targeted case management, was authorized with the passage of the Consolidated Budget and Reconciliation Act of 1985. Under this option, case management services may be provided to targeted Medicaid recipients to help them gain access to medical, social education, and other services. Previously, states could manage recipients' care through administrative methods or could provide case management through waivers. Targeted case management can help ensure continuity of care for disabled children under the TEFRA option.

A package of 1986 amendments to the Education of the Handicapped Act also are important for children subject to Medicaid home care options. These amendments require states to extend free and appropriate public education with related services to disabled preschoolers between the ages of three and five by 1990. They also allow states to establish comprehensive early intervention programs for developmentally delayed children up to three years of age. Programs may include preschool and other services to assist children and their families. States establish their own definitions of developmentally delayed or at risk of developmental delay. An Interagency Coordinating Council advises the lead state agency on planning programs and determining payment sources for services to these children (see Appendix B). States rely on

Medicaid to pay for the functional assessments and medical needs of the disabled identified through these programs.

Also in 1986, the problems of caring for babies with Acquired Immunodeficiency Syndrome (AIDS) were addressed through additional authority for home- and community-based waivers targeted to persons with specific illnesses. Any illness may be specified, but AIDS and AIDS Related Complex (ARC) are most frequently designated. Many of these waivers include disabled children.

As this progression of amendments suggests, there has been increasing support for assisting disabled children and for helping families in their care and education. Measures to expand coverage and assistance continue to be discussed in congressional committees, but further legislative action on behalf of disabled children may be curtailed because of federal budgetary concerns.

The waiver and state plan options currently in law have been aggressively pursued by the vast majority of Medicaid agencies. Programs throughout the country have developed waivers, selected optional coverages, and coordinated with Maternal and Child Health, Children with Special Health Needs, and state education agencies to structure medical and social support programs for Medicaid recipients. Disabled children often have been the focus of such activities.

2. Options for Home Care

NGA Survey on Medicaid Home Care Options for Disabled Children

State programs and experiences described in this report are based on responses to a written survey of Medicaid agencies as to their coverage of medical and support services to community-based disabled children. As part of the State Medicaid Information Center's 1989 activities, the Health Care Financing Administration requested an analysis of states' use of the TEFRA home care option. After preliminary analysis, NGA decided that study of both the TEFRA option and HCBS waivers would provide a more complete analysis of home care opportunities for disabled children.

Fifty states and the District of Columbia were surveyed and all but three jurisdictions responded. Medicaid program staff were requested to provide program information and documentation on Medicaid coverage of medical, home health, and supportive services to home- or community-based children. They were asked to describe how regular state plan services, the TEFRA option, and home- and community-based waivers are used to provide home care services. States also were asked to supply program characteristics, data on covered individuals, and expenditures. They also were queried as to why various options were pursued, and how different programs and agencies were coordinated to support home care options.

For program activities coordinated with Maternal and Child Health or other agencies, Medicaid staff were asked to provide contacts in those agencies. In some cases, the survey was completed by staff in the related agencies. Medicaid personnel and many of these contacts were telephoned for further program clarification and analysis. With the support of several state program officials, a few families participating in home care programs were visited. Discussions with the families and state officials served to further clarify issues in program implementation and care coordination.

Because each state's Medicaid program is unique and methods of program administration and analysis differ, comparisons across states are sometimes difficult. However, the survey responses indicate that there are some common policy, planning, and implementation issues to be addressed by states. Examining the similarities and differences among states' experiences with serving disabled children provides insights into the current status of family-centered, community-based care systems and issues affecting the effective implementation of such systems.

Home- and Community-Based Services Waivers

Home- and community-based services waivers offer avenues for state policymakers to respond to the long-term care needs of Medicaid recipients. Under these waivers, states can avoid some of the high costs of institutional care while providing individuals appropriate care in a home or community setting. Waivers also afford the opportunity to offer target recipients specialized services, in addition to regular Medicaid services. Because states often elect to waive the income deeming rules when they develop waivers, disabled children can more easily access such waivers and benefit from their specialized services.

Almost all states use waivers to address the special needs of some of their Medicaid population. The National Governors' Association's (NGA) May 1989 waiver analysis found that forty-seven states were operating a total of 126 waivers. Of these waivers, ninety-nine were "regular" waivers and twenty-seven were "model" waivers (NGA 1989, as found in Appendix C). These waivers target various groups such as the aged, mentally retarded, and physically disabled. The total number of individuals participating in waivers is approximately 100,000 (HCFA 1989).

Populations and Services. Responses to NGA's Survey on Medicaid Home Care Options for Disabled Children and HCFA's September 1989 list of approved waivers found that 52 percent of all waivers include children. Currently, thirty-six states operate a total of sixty-six waivers that include children among their participants. Forty-two are regular waivers and twenty-four are model waivers (see Table 1). Because waiver data are not age-specific, it is difficult to determine exactly how many children are served under these sixty-six waivers. However, it is clear that waivers are widely used to care for disabled children.

Among the forty-two regular waivers that include children are twenty-one (50 percent) that target the mentally retarded and/or the developmentally disabled, six that focus on individuals with AIDS or ARC, and three that are solely for disabled children. The services most commonly offered under these waivers are case management (85 percent) and respite care (79 percent). Other popular services include habilitation (62 percent), homemaker (45 percent), and personal care services (45 percent). The number of persons served ranges from fewer than fifty up to several thousand. The number of waiver "slots" is negotiated with HCFA at the time of application (see Table 2).

The regular waivers that specifically target disabled children vary considerably. For example, New Mexico's waiver covers an array of services, including case management; respite, homemaker, personal care, and psychosocial services; private duty nursing; and physical therapy. Maryland's waiver covers case management, private duty nursing, and durable medical equipment and supplies. Texas' waiver primarily provides respite care.

Almost all of the twenty-four model waivers include children in their target group. Eight target disabled children (33 percent), seven are for the mentally retarded or developmentally disabled (29 percent), and three target blind individuals. The eight waivers for disabled children include two solely for children with AIDS. As with regular waivers, case management (71 percent) and respite care (54 percent) are the

New Mexico's Medically Fragile Children's Program

In operation since August 1984, this home- and community-based waiver provides home care to chronically ill and developmentally disabled children up to age nineteen. All must be medically fragile; some require mechanical support devices. The Medically Fragile Children's Program (MFCP) is one of four waivers offering home care options to disabled children in New Mexico.

MFCP is administered by the state human services department, which establishes eligibility criteria, reimbursement rates, provider standards, and other procedures; monitors service quality; and approves new applications. The program has a strong consumer orientation since parents worked with the state in its development.

Waiver services include case management; private duty nursing; homemaker/personal care and in-home respite services; occupational, speech, physical, and psychosocial therapies; institutional respite care; and environmental modifications to the home.

A detailed analysis of the program in 1986-87 revealed that nine families had incomes of $10,000 or less and five had incomes above $30,000. Approximately 60 percent were covered under a private health insurance plan. Most insurance coverage was limited to technical equipment, although some families had partial coverage of in-home nursing care. Some 40 percent of the families reported receiving some home care services other than those provided through MFCP or the local school system. A wage earner in 60 percent of the families had quit a job or limited employment hours in order to provide care for the medically fragile child.

Program costs among MFCP participants varied substantially. Four children incurred average costs of under $500 per month, while six children averaged over $1,700 per month. The average total cost to Medicaid of an MFCP recipient was $21,832 per full year of enrollment—$16,680 for MFCP services and $5,152 for regular Medicaid acute care services. The total home care cost was about 66 percent of the annualized intermediate care facility for the mentally retarded (ICF/MR) reimbursement of $33,196, which was the amount used to determine the cost-effectiveness standard for program participants.

The average Medicaid cost per month of enrollment was $1,390. Of this cost, private duty nursing accounted for 67 percent ($932/month), case management for 24.3 percent ($338/month), and therapies for 7 percent ($120/month) of Medicaid payments. Families received an average of 78.9 hours of private duty nursing care per month and 8.5 hours of case management services.

Families considered case managers extremely helpful during the application process and also indicated that they allowed them adequate control over services delivered throughout the program. Nearly all families found the quality of care excellent or good.

The state expanded its waiver this year to include up to sixty-seven children, an increase of fifty-nine over the first waiver year. New Mexico's commitment to caring for disabled children at home continues to increase.

most prevalent services. Model waivers generally include fewer services than regular waivers. Some model waivers serve only a handful, although most are authorized to serve fifty persons. Several states, including New York and Rhode Island, have taken advantage of the new 200-person limit and have expanded their waivers up to the ceiling (see Table 3).

Waiver Application. Regular waivers are approved by the Health Care Financing Administration for a three-year period and, at the state's request, may be renewed for a three- or five-year period. For HCBS waiver approval or renewal, states must demonstrate that the program of home services will be cost-effective. Using the HCFA-specified formula, cost-effectiveness must be proved at the end of each waiver year and for renewal purposes. Model waivers follow the same procedure. However, they require less information for approval and are given priority in the review process. The cost-effectiveness test is the same.

Eligibility Determination and Care Development. Individuals may qualify for participation in a HCBS waiver by meeting the disability definition and level of care criteria specified in the waiver as well as applicable income and resource standards, and by accessing an open waiver slot. Generally, income and resource standards are those used for the SSI program, because those are the criteria used for institutionalized individuals. At the state's discretion, income up to 300 percent of SSI levels may be allowed. The state may select varying income standards for different waivers. If the waiver is at maximum capacity, an individual must wait for someone to die or become ineligible for the waiver before gaining access to the waiver and its services.

Once a waiver slot is open, an individual's application for the waiver will be reviewed. Financial eligibility usually is determined by the local social services or Medicaid office. Disability must be verified by Medicaid or by the agency determining disability for the SSI program, which may be the social services department or an agency contracted by the state to make such determinations. The level of care that would be required if the individual were institutionalized also must be determined. Level of care determinations generally are conducted by Medicaid or the division of the state health department that surveys and certifies nursing homes, and the individuals residing in them.

After these determinations are made, the Medicaid agency develops a care plan or reviews the physician's or home health provider's treatment plan for the individual. Plans are reviewed for appropriateness and adequacy of home care services. They also are reviewed for cost-effectiveness, which involves a comparison with institutional care costs and/or a state-established limit on expenditures per individual under the waiver. If the care plan exceeds cost limits, services paid for by other programs or state agencies may be identified to supplement the care plan in order to achieve a plan that ensures adequate and appropriate home care.

Typically, persons at home under HCBS waivers are monitored by case managers who assist in coordinating home care providers and in finding new providers if necessary. Case managers periodically review care plans and care needs, recommending increased or reduced services when appropriate. The case managers also coordinate periodic reviews of an individual's financial situation, disability, and care plan, which are necessary for continued waiver participation. Annual reviews usually repeat the initial review sequence.

Notwithstanding administrative problems, waivers have proved highly useful for state experimentation with cost-effective home care delivery for selected portions of the Medicaid population. Waivers have repeatedly demonstrated the benefits of case management and cost containment. They have fostered new cooperation between Medicaid and departments of public health, mental retardation and developmental disabilities, mental health, and children with special health care needs. Such cooperation reduces fragmentation and duplication of effort, which contributes to improved care plans. Most important, waivers have provided opportunities for many children to remain in their homes with their families.

Table 1
Population and Services Under Home- and Community-Based Waivers Serving Disabled Children[1]

Home- and Community-Based Waivers Serving Disabled Children

POPULATION	TOTAL WAIVERS*	CASE MNGT.	HOME-MAKER	HM. HLTH. AIDE	PERS. CARE	ADULT DAY	HABILITATION	RESPITE CARE	TRANSPORT	HOME MOD.	OTHER
MR/DD	21	18	6	1	6	3	19	17	5	2	9
A/D	11	9	8	1	7	7	4	10	6	2	5
AIDS/ARC	6	6	4	0	5	2	2	3	2	2	4
C/D	3	2	1	0	1	0	0	2	0	0	2
MI	1	1	0	0	0	1	1	1	0	0	0
TOTALS	**42**	**36**	**19**	**2**	**19**	**13**	**26**	**33**	**13**	**6**	**20**

* Twenty-eight states have a total of forty-two home- and community-based waivers.

Home- and Community-Based Model Waivers Serving Disabled Children

POPULATION	TOTAL WAIVERS*	CASE MNGT.	HOME-MAKER	HM. HLTH. AIDE	PERS. CARE	ADULT DAY	HABILITATION	RESPITE CARE	TRANSPORT	HOME MOD.	OTHER
MR/DD	7	5	4	1	4	2	3	5	3	3	4
C/D	6	3	0	0	0	4	0	4	0	0	5
D	5	5	2	0	1	0	1	2	0	1	3
B/D	3	3	0	0	0	0	0	0	0	0	2
AIDS C/D	2	1	0	1	0	0	0	2	0	0	2
VENT. DEP.	1	0	0	0	0	0	0	0	0	0	1
TOTALS	**24**	**17**	**6**	**2**	**5**	**6**	**4**	**13**	**3**	**4**	**17**

* Twenty states have a total of twenty-four home- and community-based model waivers.

KEY: A/D = Aged/Disabled, AIDS/ARC = AIDS/AIDS Related Complex, C/D = Child/Disabled, MI = Mentally Ill, MR/DD = Mentally Retarded/Developmentally Disabled

NOTES: (1) Source: September 1, 1989 Waiver List of the Office of Coverage Policy, Health Care Financing Administration and the NGA Survey on Medicaid Home Care Options for Disabled Children.

Table 2
Populations and Services Under Home- And Community-Based Waivers Serving Disabled Children By State[1]

STATE	EFF. DATE (2)	POPU-LATION	CASE MNGT.	HOME-MAKER	HM. HLTH. AIDE	PERS. CARE	ADULT DAY	HABILI-TATION	RESPITE CARE	OTHER (3)	TOTAL SERVED (4)	WAIVER YEAR
AL	10/4/84	A/D	X	X		X	X	X	X	X	3,808	'87
AR	1/1/89	MR/DD	X					X	X	T	150	----
CA	1/1/89	AIDS/ARC	X	X						H	----	----
FL	4/1/82	MR/DD	X						X	T	2,631	'87
	9/1/89	AIDS	X	X		X			X	H,X		
HI	8/15/83	A/D	X	X		X	X	X	X	T,X	306	'87
	4/1/88	AIDS/ARC	X			X		X	X	T	----	----
ID	1/1/84	A/D,MR/DD				X					236	----
KY	4/1/83	MR/DD	X	X	X	X	X	X	X	X	637	'86
	7/1/83	A/D	X	X		X	X		X	H	286	'87
ME	7/1/83	MR/DD	X					X	X	T	----	----
MD	1/1/88	C/D	X								----	----
MN	7/1/84	MR/DD	X	X				X	X	X	991	'87
	10/1/87	D	X	X		X	X	X	X		----	----
MO	1/1/84	A/D	X	X					X	T	34	'87
	7/1/89	AIDS/ARC	X	X		X	X	X	X	T,X		
MT	7/1/83	MR/DD	X	X		X	X	X	X	X	210	'87
NE	10/1/87	MR/DD	X					X		X	----	----
NV	7/1/82	MR/DD	X					X			135	'87
NJ	10/1/82	MR/DD	X			X		X	X		151	----
	10/1/83	A/D	X	X					X	T	2,197	'86
	3/1/87	AIDS/ARC	X			X				X	112	----
NM	7/1/83	A/D	X	X			X		X	T	438	'87
	7/1/87	AIDS/ARC	X	X		X	X			X	----	----
	8/1/84 (5)	C/D	X	X		X			X	X	28	'88
	7/1/83	MR/DD	X	X		X		X	X	X	117	'87
NY	12/2/82	A/D							X	T, X	4,453	'86
NC	7/1/83	MR/DD	X	X		X		X	X	X	306	'87
OH	7/1/84	A/D	X	X	X	X	X		X	X	613	'87
OK	1/1/85	MR		X				X	X	X	451	'87
PA	10/1/86	MR	X				X	X	X	T, H	----	----
SD	6/1/82	MR/DD	X					X		X	622	'87

STATE	EFF. DATE (2)	POPU-LATION	CASE MNGT.	HOME-MAKER	HM. HLTH. AIDE	PERS. CARE	ADULT DAY	HABILI-TATION	RESPITE CARE	OTHER (3)	TOTAL SERVED (4)	WAIVER YEAR
TX	9/1/85	MR/DD	X	X				X	X	X	157	'87
	6/29/88	C/D							X	X	----	----
UT	7/1/87	MR/DD						X	X		----	----
VT	4/1/82	MR/DD	X				X	X	X	T	205	'87
	4/1/82	MI	X				X	X	X	T	77	'87
VA	6/18/82	A/D				X					3,715	'87
WV	7/1/82	MR/DD	X					X	X	T	87	'87
WI	1/1/87	A/D	X			X	X	X	X	T, H, X	----	----
	10/6/83	MR/DD	X					X	X	H	233	'86
	8/1/87	MR/DD	X					X	X	H	----	----

KEY:
- A/D = Aged/Disabled
- AIDS/ARC = AIDS/AIDS Related Complex
- C/D = Child/Disabled
- MI = Mentally Ill
- MR/DD = Mentally Retarded/Developmentally Disabled

NOTES:
(1) Source: September 1, 1989 Waiver List of the Office of Coverage Policy, Health Care Financing Administration and NGA Survey on Medicaid Home Care Options for Disabled Children.

(2) Reflects the effective date of the first waiver developed for this group.

(3) Key: T = Transportation, H = Minor Home Modification, and X = Other, which includes one or more of the following: psychosocial counseling, client support services, clinical support services, nutritional assessment, special drugs, medical supplies, prevocational services, supported employment, emergency response systems, nonmedical transportation, or any other service approved by HCFA.

(4) The total number of adults and children served in the waiver year indicated is based on HCFA's Bureau of Quality Control's list of HCFA-372 Reports accepted in fiscal 1988.

(5) This waiver began as a model home-and community-based waiver.

Table 3
Populations and Services Under Home- and Community-Based Model Waivers Serving Disabled Children[1]

STATE	EFF. DATE (2)	POPU-LATION	CASE MNGT.	HOME-MAKER	HM. HLTH. AIDE	PERS. CARE	ADULT DAY	HABILI-TATION	RESPITE CARE	OTHER (3)	TOTAL SERVED (4)	WAIVER YEAR
CT	10/1/83	MR/DD; D	X							X	16	----
GA	9/1/84	C/D	X						X	X	3	87
IL	7/1/85	AIDS C/D			X				X	X	----	----
IA	8/1/84	C/D; MR/DD		X	X	X	X		X	X	36	87
KY	8/1/87	C/D								X	1	----
	10/5/87	VENT.DEP.								X	3	---
MD	1/1/85	C/D	X							X	----	----
MI	10/1/85	MR/DD							X	X	1	'85
MN	4/1/85	D	X	X	X				X	H, X	18	'87
NE	6/1/89	MR/DD	X	X			X	X	X	T, H, X		
NV	10/1/89	D	X	X							----	----
NJ	9/1/83	B/D	X								22	----
	4/1/85	B/D	X							X	18	'87
	4/1/86	B/D	X							X	36	'86
NY	12/1/85	C/D	X						X		7	'85
NC	7/1/83	AIDS C/D	X						X	X	----	----
OH	10/1/83	MR/DD	X	X		X		X	X	T	40	'86
	10/1/83	MR/DD	X	X		X		X	X	T, H	25	'86
PA	7/1/87	D	X							X	----	----
RI	4/1/86	D	X			X				X	50	----
SC	1/1/87	C/D							X	X	----	----
TN	7/1/86	MR/DD	X			X				H	50	----
VA	1/31/88	C/D							X	X	----	----
WA	12/1/87	D	X					X	X	X	----	----

KEY: A/D = Aged/Disabled, AIDS/ARC = AIDS/AIDS Related Complex, C/D = Child/Disabled, MI = Mentally Ill, MR/DD = Mentally Retarded/Developmentally Disabled

NOTES:

(1) Source: September 1, 1989 Waiver List of the Office of Coverage Policy, Health Care Financing Administration and NGA Survey on Medicaid Home Care Options for Disabled Children.

(2) Reflects the effective date of the first waiver developed for this group.

(3) Key: T = Transportation, H = Minor Home Modification, and X = Other, which includes one or more of the following: psychosocial counseling, client support services, clinical support services, nutritional assessment, special drugs, medical supplies, prevocational services, supported employment, emergency response systems, nonmedical transportation, or any other service approved by HCFA.

(4) The total number of adults and children served in the waiver year indicated is based on HCFA's Bureau of Quality Control's list of HCFA-372 Reports accepted in fiscal 1988.

TEFRA State Plan Option

The TEFRA state plan option offers another avenue for providing cost-effective home care to recipients. Like most HCBS waivers, the TEFRA option allows states to ignore parental income and resources when determining eligibility for home care. Unlike HCBS waivers, the TEFRA option allows access only to services regularly available under the Medicaid state plan. However, it provides that access to all disabled children under age eighteen who meet an institutional level of care need and cost-effectiveness criterion, as there is no ceiling on the number who can be served. Essentially, this option allows states to extend regular Medicaid to children who would be eligible if they were in an institution, such as a hospital, intermediate care facility, intermediate care facility for the mentally retarded, or skilled nursing facility. The TEFRA option is easier to implement than HCBS waivers because no application is necessary. However, the TEFRA option does not hold the flexibility to target groups and services.

Populations and Services. Seventeen states have selected the TEFRA state plan option (see Table 4). State estimates indicate that approximately 4,000 children access Medicaid through this option. This amount represents an elevenfold increase over 1986 estimates, when ten states had the TEFRA option under their state plans (Fox 1986). Although ten states had officially adopted the option, most of these programs were new. Since 1986, program growth has been steady in most states. Minnesota and Wisconsin currently have the largest number of children participating.

TEFRA option children suffer from the entire range of disabling conditions qualifying individuals for SSI program coverage. State survey responses indicate that a majority of children have more than one medical complication usually resulting in some degree of developmental delay. Most TEFRA states consider these children chronically ill rather than mentally retarded or developmentally delayed, although states with larger populations report higher numbers of these individuals within the TEFRA group.

Limited program experience and data make it impossible to determine the average period of eligibility through the TEFRA option. However, anecdotal information from states indicates that some children improve and no longer require home care, some improve and no longer meet the required institutional level of care need, some reach age nineteen and no longer meet the age requirement, and some die as a result of their illnesses. Of course, many children thrive in home-care settings and continue to access such care for extended periods.

Twelve states that have adopted the TEFRA option also have targeted case management programs benefitting some of these same children. Thirteen states operate HCBS waivers that include disabled children, in addition to their TEFRA program.

TEFRA Option Selection. States select the TEFRA option by checking a box on their preprinted state plan form; no other application is required. States using an income standard above the regular SSI program standard (up to 300 percent) must use that higher standard in determining children's eligibility. Cost-effectiveness is determined individually for each child. While there is no specified cost-effectiveness

Table 4
Medicaid Home Care Options for Disabled Children by State

	TEFRA Option (1)	Number of TEFRA Children (2)	2176 Waiver (3)	2176 Model Waiver (4)	Targeted Case-Management Options (5)
Alabama			Y	N	CMI, SED Children
Alaska			N	N	N
Arizona			N	N	N
Arkansas	85	227	Y	N	
California			Y	N	
Colorado			N	N	
Connecticut			N	Y	N
Delaware	86	194	N	N	
District of Columbia			N	N	N
Florida			Y	N	Disabled Children
Georgia	82	84	N	Y	CMI, MR/DD
Hawaii			Y	N	N
Idaho	84	226	Y	N	N
Illinois			N	Y	N
Indiana			N	N	Pediatric AIDS
Iowa			N	Y	CMI, MR, DD, Pregnant Women
Kansas			N	N	MI, CMI,Vent-Dep.Children
Kentucky			Y	Y	Disabled Children
Louisiana			N	N	Ventilator-Dependent
Maine	83	160	Y	N	CMI, MR/DD, HIV, Dev-Delayed
Maryland			Y	Y	HIV, Pregnant Adolescents under 18
Massachusetts	87	140	N	N	Physician Plans
Michigan	87	92	N	Y	MI, MR/DD, Medically Fragile
Minnesota	88	950	Y	Y	CMI
Mississippi	89	20	N	N	High-risk Pregnant Women & Children
Missouri			Y	N	At-risk Pregnant Women & Children
Montana			Y	N	N
Nebraska	88	9	Y	Y	A/B/D,AFDC
Nevada	82	27	Y	Y	N
New Hampshire	89	16	N	N	CMI
New Jersey			Y	Y	N
New Mexico			Y	N	N
New York			Y	Y	Community MRs,CMI,
North Carolina			Y	Y	SED,CMI
North Dakota			N	N	N
Ohio			Y	Y	CMI, MR/DD
Oklahoma			Y	N	CMI
Oregon			N	N	DD
Pennsylvania			Y	Y	AIDS, HIV, High-risk Infants
Rhode Island	83	84	N	Y	CMI
South Carolina			N	Y	MR/DD
South Dakota	86	2	Y	N	N
Tennessee			N	Y	N
Texas			Y	N	CMI,MR
Utah			Y	N	Function. Impaired, Disabled,DD
Vermont	87	28	Y	N	CMI,MR
Virginia			Y	Y	Pregnant Women & Children up to age 2
Washington			N	Y	AIDS, Adolescent Parents & under 21
West Virginia	85	2	Y	N	CMI,MR/DD
Wisconsin	83	1515	Y	N	CMI,MR/DD,SED Children
Wyoming			N	N	N
TOTALS	17	3776	28	20	32

KEY:

Y	= One or more waivers
N	= No waivers
CMI	= Chronically Mentally Ill
SED	= Severely Emotionally Disturbed
MR/DD	= Mentally Retarded/Developmentally Disabled
A/B/D	= Aged/Blind/Disabled
AFDC	= Aid to Families with Dependent Children
AIDS	= Acquired Immunodeficiency Syndrome
VENT-DEP.	= Ventilator-Dependent
DEV. DELAYED	= Developmentally Delayed

NOTES:

(1) Also known as the Katie Beckett Option. This column shows the year in which coverage under the option began.

(2) Number of children accessing Medicaid through the TEFRA option based on state estimates.

(3) Presence of waiver including coverage of disabled children. Source: NGA's Status of Home- and Community-Based Waivers, September 1, 1989 and NGA Survey on Medicaid Home Care Options for Disabled Children.

(4) Presence of model waiver including coverage of disabled children. Source: NGA's Status of Home- and Community-Based Waivers, September 1, 1989 and the NGA survey.

(5) Presence of targeted case management option including coverage of disabled children.

formula, states are bound by law to limit Medicaid coverage under this option to children whose estimated cost of care at home is equal to or less than the cost of that care in an institution. At the time of a program audit, states simply must be able to demonstrate cost-effectiveness.

Eligibility Determination and Care Development. The application and review processes in many ways parallel states' procedures for establishing eligibility under a HCBS waiver. Reviews for compliance with disability definition, income and resource standards, and cost-effectiveness are conducted. Unlike the waiver program, states do not maintain lists of children awaiting open "slots." When children meet the criteria, they immediately access regular Medicaid. However, while access to Medicaid may be easier under the TEFRA option, services to these children may be more limited than those available to like children in the same state who participate in a HCBS waiver program.

States have developed varying methods to process and evaluate children's Medicaid eligibility (see Table 5). Twelve states begin the eligibility process at the local social services or Medicaid office. Five states begin the application process with specialized TEFRA program staff. Although a family may learn of the program through hospital personnel or through the local welfare or public health office, they begin their application with TEFRA program staff who, if not in a central office, are coordinating with central office staff. If the process begins with specialized program staff, it usually is carried through and reviewed by them annually.

In the states beginning the process at the local office, it is most likely that the local office eligibility worker has initial responsibility for gathering financial and

Table 5
Eligibility Processing of Disabled Children Under the TEFRA State Plan Option

TEFRA OPTION STATE	INITIAL APPL. LOCATION	DISABILITY DETERMINATION	CARE PLAN DEVELOPER	LEVEL OF CARE REVIEW	CARE PLAN REVIEW	COST-EFFEC-TIVENESS APPROVAL	FAMILY/ HOME ASSESMNT	CARE COORD.	CASE REVIEW
AR	Local office.	Medical Review Team (DHS).	Physician.	TEFRA team.	TEFRA team in Children's Medical Services.	Utilization Review member of TEFRA team.	TEFRA Team.	Local office Case Worker.	TEFRA team annually.
DE	Local office.	Phys. Consultation & Administrator for MCH.	Phys. submits med. information to local office.	Phys. Consultation & Administrator for MCH.	Medicaid's Physician Consultant & Senior Administrator for MCH.	Phys. Consultation & Administrator for MCH.	Social worker in field office.		Repeat initial review process annually.
GA	Local office.	State Medical Review Team.	Physician.	GA Medical Care Foundation.	GA Medical Care Foundation.	Presume cost-effectiveness.	Home Health Provider.	Local office.	Local office coordi-nates. Same as initial review.
ID	Local office.	Care Patient Assmt. Desk (CPAD) at Social Security.	Phys. Final Home Care Package developed by Child Protective Case Worker.	Dept. of Human Services' Inspection of Care Nurse.	CPAD at Social Security.	Medicaid.		Family.	Medicaid.
ME	Local office.	Medical Review Team in state office.	Physician.	Bur. of Medical Serv. Consumer Services.	Consumer Services.	Consumer Services.	None.	Case Manager.	Local off. conducts financial redetermin-ations. Consumer Serv. Div. Every 3 mos. for SNF level plans; every 6 mos. for ICF levels.
MA	Kalleigh Mul-ligan (KM) Program staff.	Disability Determina-tion Services.	Dept. of Public Health (DPH) Case Mgr.	KM Program staff & Med. Review Team, which includes 2 DPH clinicians.	KM Program staff.	KM Program staff.	DPH Case Manager.	DPH Case Manager.	KM Program staff annually. Local off. makes financial re-determination every 6-12 months.
MI	Children's Special Health Care Serv. Prog. (CSHCS).	State Medicaid Agency.	CSHCS Care Mgr. coordinates multidisciplinary team.	CSHCS.	CSHCS.	CSHCS, subject to state Medicaid review.	CSHCS Care Manager.	CSHCS Care Manager.	CSHCS recertifies care plan. County DSS conducts income re-determination.
MN	Local office.	State Medical Review Team.	Phys/Home Care Provider.	Three methods depending on the client.		Retrospective (post payment) review; prior authorization.	Public Health Nurse or Soc. Services.	Public Health Nurse or social servs. referral.	Local office.
MS	Local office.	Disability Determina-tion Services.	Phys. submits medical info. with application.	Survey Agency in State Health Dept.		Presume cost-effectiveness.			Local office conducts redetermination.

TEFRA OPTION STATE	INITIAL APPL. LOCATION	DISABILITY DETERMINATION	CARE PLAN DEVELOPER	LEVEL OF CARE REVIEW	CARE PLAN REVIEW	COST-EFFECTIVENESS APPROVAL	FAMILY/ HOME ASSESMNT.	CARE COORD.	CASE REVIEW
NE	Central office.	Team.	Team which includes central & local office staff, phys., home health agency, & parents.	Team.	Team.	Team.	Team.	Team.	Team.
NV	District office.	Phys. & social worker from Sec. 1902(e)(3) Board.	Physician.	1902(e)(3) Board.	1902(e)(3) Board.	1902(e)(3) Board.	1902(e)(3) Board.		
NH*	Local office.	Medicaid joint medical review team.	Physician submits medical information	Medicaid joint medical review team.	Medicaid joint medical review team.	Cost-effectiveness determined retrospectively.	Medicaid joint medical review team.		Local off. conducts financial redetermination every 6 mos. Med. redetermination dates assigned by Med. Review Team.
RI	Regional office.	Regional office.	Phys. submits medical info.	Long-term care unit.				Regional office.	Regional office.
SD	State office	State office R.N.	Physician	State office R.N.	State office R.N.	State office R.N.			
VT	Dept. of Social Welfare Local office.	Disability determination Services.	Team including: Medicaid Div. Medical Review Unit, hospital discharge planner, private insurer, phys., DME supplier, Health Dept, Educ. Dept., and parents.	Medicaid.	Team.	Team.	Team.	Medical Equip. certified as technology dependent client prov.	Medicaid Div. & private insurer. Every 2 wks. initially, then every 4-6 wks.
WV	Local office.		Physician.	Medicaid.	Medicaid Case Planning nurses.	Medicaid.	Local office social worker.	DME provider.	Local office.
WI	Katie Beckett program office.	Disability determination unit in vocational rehabilitation.	Phys., family, and community provider	K. Beckett program office.	K. Beckett program office.	K. Beckett program office.	K. Beckett program office.		K. Beckett program staff conducts care plan reviews & financial redeterminations annually.

NOTE: In New Hampshire, children must meet the Children with Severe Disabilities criteria and access Medicaid through this classification of AFDC children.

Wisconsin TEFRA Option Program

One of the first states to select the TEFRA state plan option, Wisconsin now serves over 1,500 disabled children in its Katie Beckett Program. As with most of the larger TEFRA programs, Wisconsin's Katie Beckett Program is operated primarily through the state office with a specially designated staff.

The program is based in the community services division of Wisconsin's Department of Health and Social Services (DHSS). Three registered nurses process all cases, including review and approval of care plans as well as family evaluations. They conduct annual financial redeterminations and care plan reviews. The health care financing bureau processes all claims.

Of the children in Wisconsin's program, approximately 50 percent are male and 50 percent female. Most children are under age six. In fiscal 1988, program expenditures were nearly $6 million for a caseload of approximately 1,200 children. Medicaid expenditures are primarily supplementing private insurance dollars, averaging less than $10,000 per case. Approximately 80 percent of these children have insurance when they are referred to the program.

As with other mature TEFRA programs, most children being added to the program already live in the community. As programs become well known, the trend seems to be that informed hospital discharge planners are less frequently arranging medical support for families, but more frequently are families applying for the program after learning of it through home health agencies, schools, or parent support groups.

Program staff indicate some problems with registered nurse and home health aide shortages, especially in rural areas. Additionally, there are insufficient numbers of physical therapists, respiratory therapists, and speech therapists who are adequately trained and comfortable working with medically complex children.

Despite provider shortages and difficulties arranging for families' nonmedical needs, Wisconsin considers the program to be cost-effective for the Medicaid program. At the same time, it has enhanced the quality of life for many children and has maintained the integrity of their family unit.

disability information from the physician and family. The worker then turns that information over to central office staff who coordinate the remaining reviews. The case may or may not come back to the local office for periodic or annual reviews.

In these same states, the child's home care needs are specified by the physician and/or home health provider on the initial application or in a treatment plan attached to the application. In states using the centralized TEFRA program system, the care plan is more likely to be developed by specialized program staff in conjunction with providers and families.

Regardless of who develops the care plan, its purpose is the same: a comprehensive plan of care for the child and support for the family in caring for the child at home. The plan identifies all personnel and supply needs as well as the providers who will supply them.

The level of care assessment seems to mark another divergence among states in the handling of these cases. This step requires review of the medical condition and the level of assistance needed in major activities, which is required to determine the equivalent institutional level of care. The level of care determination dictates the Medicaid cost for the child if institutionalized, an amount used later in assessing cost-effectiveness. Level of care assessments generally are conducted by central office personnel. States with centralized programs tend to make these assessments themselves. Other states rely on personnel brought together to evaluate TEFRA cases or on regular state survey teams whose normal duties encompass surveying and certifying institutions for participation in the Medicaid program.

Review of the care plan for adequacy and appropriateness is the next step. In most states, the same individuals determining level of care review care plans for comprehensiveness. Although the care plan may have been developed by the physician, or from information submitted by the physician, at this point in the process most states have a multidisciplinary team review the plan. Teams usually include a physician, home health nurse, and the parents. Additional parties, such as the hospital discharge planner, primary home health provider, physical therapist, durable medical equipment supplier, education department representative, or social worker, may be added or consulted depending on the child's condition.

Eleven states include formal or informal family/home assessments as part of the case evaluation. In some states the family assessment is made by a social worker or eligibility worker in the local Medicaid office. In other states the assessment is made by the multidisciplinary review team based on information supplied by the physician, hospital, or other professional staff having contact with the family. Frequently, children applying for coverage under the TEFRA program already are known to state personnel because of coverage under other state assistance programs or because of other Medicaid coverage. In such cases, state staff can readily make their assessment based on their familiarity with the family. The degree to which family/home assessment plays a role in approval of the child for at-home care varies among states.

The review for cost-effectiveness tends to be conducted by these same individuals. If the care plan service requirements include non-Medicaid services, exceed Medicaid limitations for specific services, or exceed what Medicaid can pay given cost-effectiveness limitations, the team must enlist other programs or private insurers. Relevant private insurers are requested to pay for essential services covered in their benefit package. State-funded medical assistance services or other state programs are used to pay for or provide the additional services. Although most review teams will evaluate cost-effectiveness at this point, in four states cost-effectiveness is determined after care has been provided. These states presume that all home care cases are less expensive than institutional cases, and that postpayment annual reviews are sufficient to confirm their cost savings.

After all assessments and reviews, cases tend to be turned over to the local office for processing of the child's actual enrollment in the Medicaid program. The child receives a Medicaid card, which is used for all Medicaid-covered services in the care plan.

Once the child is on Medicaid, most states monitor and evaluate continued eligibility through care coordination and annual reviews. Ten states report that they provide care coordination or case management services for most of these children. Eight states provide case management through local office personnel. Two states rely on the primary home health provider to alert them to care coordination problems. One state specifies that the family is responsible for managing all care and providers delivering care in their home.

Depending on state practices, financial redeterminations occur every three months, six months, or annually. Care plans generally are reviewed when a child's health status changes and then annually. Typically, annual reviews follow review

procedures used for initial applications and require updating of all documentation on the child.

Whether the state uses a centralized application approach or assigns pieces of that process to appropriate units within the social services network, the result is the same: Medicaid enrollment for disabled children who can be cared for cost-effectively at home through regular Medicaid services. While eligibility processing is often as complex as under HCBS waivers, the absence of a program application and annual cost savings tests, makes the TEFRA option attractive to many states and to the children who gain Medicaid access through this option.

3. State Experiences in Home Care

The HCBS and TEFRA options present significant policy and program development, implementation, and analysis challenges. Eligibility, service, and reimbursement issues are complex and interrelated, primarily because of these options' underlying cost-effectiveness criteria. Negotiating these obstacles and successfully implementing quality programs constitutes a difficult task. However, states can build upon their own experience, as well as that of other states, to develop manageable programs providing increased opportunities for disabled children to benefit from quality home care.

Home- and Community-Based Services Waivers

Home- and community-based services waivers are not the answer to all long-term care needs, but they provide a partial solution for populations who can appropriately be cared for in the community. Since approval of the first HCBS waivers seven years ago, states have learned a great deal about the role waivers can play in their Medicaid program, and about how to structure them for optimum effectiveness in carrying out that role.

Target Groups and Services. Waivers offer substantial flexibility to target specific populations and to fashion innovative, coordinated home care programs to meet most of their medical and some of their nonmedical needs. The flexibility originates in the law, which, for the purposes of these programs, allows the "waiving" of the two Medicaid rules that states must provide comparable services and provide them to all qualified individuals throughout a state. When designing a waiver program, states always waive the first rule on comparability, but they may or may not choose to waive the second rule on "statewideness." It is the waiving of the comparability rule that allows a state to provide services in greater quantity and/or scope than are permitted under its regular Medicaid program. Waiver of this rule also permits the provision of specialized services such as respite care, minor home modifications, case management, and transportation. It is the waiver of the statewideness rule that permits a state to design a program for a specific geographic area.

Waivers afford states the opportunity to focus on different categories of individuals and their varying service needs. The mentally retarded/developmentally disabled is a target group in many states that has substantial medical and nonmedical needs. In developing waivers for this population, states often provide habilitation and respite services that are not regular Medicaid services. Intensive case management may be another service. Prior to the 1985 legislative amendment, targeted case management was provided only under waivers, so it is within waiver programs that many states have developed their most intensive case management approaches.

In addition to case management, a state may provide physical, occupational, and other therapies not covered under its state plan. Additional home health and transportation services not available to regular Medicaid recipients may be offered. Finally, a state may cover minor home modifications to allow wheelchair access and electrical improvements to accommodate ventilators. Developing a MR/DD waiver permits a state to make a commitment to a subset of this population and then to expand that commitment through increasing the number of waiver slots in subsequent years.

Many states made initial commitments to disabled children through small waivers that were later expanded to encompass more children. For example, New Mexico began its Medically Fragile Children's Program with eight children in 1984. This year as many as sixty-seven children will be served under the waiver. In 1986, New York initiated a model waiver for fifty physically disabled children meeting an intermediate level of care need. The state's satisfaction with its Care At Home program led New York to expand participation to 200 children, which is the new model waiver limit. Pennsylvania recently expanded its Michael Dallas Model Waiver for Technology-Dependent Children program to 100 children.

Instead of expanding participation under an existing waiver, a state may increase its commitment to a subpopulation by adding a new waiver. Based on past experience, the state can fine-tune the new waiver further, targeting specialized services for the new subset.

Both New Mexico and New York have added waivers for additional segments of the disabled children population. New York recently added a new waiver serving 200 children requiring a hospital level of care. In 1987, New Mexico added a waiver for individuals with AIDS or ARC. New Jersey had three waivers for the blind and disabled in 1986. The following year it added a new waiver for persons with AIDS or ARC and for HIV-positive children under age five.

When several waivers are in place, a state can move individuals from one waiver to another if their needs more appropriately match services provided under the new waiver. Similarly, TEFRA option states often move TEFRA children to waivers when openings occur. This allows children with significant medical needs to access regular Medicaid coverage until waiver slots open. Children are afforded more services when they gain entry to the waiver. Minnesota reports using TEFRA for developmentally disabled children awaiting placement in its Home- and Community-Based Waiver for Persons with Mental Retardation or Related Conditions. As openings occur, Georgia moves some of its TEFRA children to the state's Community Care Program, which provides respite care and twice as many home health visits as are allowed under the regular state plan.

Waiver programs offer an opportunity to provide additional services to the most needy of a target group. Usually the type or quantity of specialized services result in significant per person costs. While the state may not have the resources to provide these services to all qualified individuals, it may be able to afford them for those with the most critical needs.

In addition to using waivers to experiment with an intensive, coordinated commitment to particular segments of its Medicaid population, states may use waivers

New Jersey's AIDS Community Care Alternative Program

New Jersey's AIDS Community Care Alternative Program (ACCAP) provides an array of services to 500 persons with AIDS or ARC and HIV-positive children under age five. Begun in March 1987, ACCAP was among the first HCBS waivers for persons with AIDS.

Based on 1987 and 1988 data on 954 ACCAP participants, 80 percent were between the ages of twenty-one and fifty, with 56 percent over thirty-six years of age. Children comprised 12 percent of the waiver population; 106 were under age thirteen, and six were between the ages of thirteen and twenty. About 75 percent of the program's participants were male. Almost two-thirds of those served and 74 percent of the minority group were black. Just over one-half were intravenous drug abusers; nearly all drug abusers were heterosexual. Incomes were primarily below poverty level; 57 percent had annual incomes of $4,788.

Almost 85 percent lived with relatives or friends or in foster care homes. Seventy-seven percent lived in the community before joining the waiver. Sixteen percent were brought home from institutional settings, and all but one of this group was hospitalized. Level of care determinations ranked 78 percent at an intermediate care facility level with the remainder at a skilled nursing facility level of care.

Waiver services include case management, private duty nursing, personal care, medical day care, drug abuse treatment, foster care, and hospice services. Of course, Medicaid's regular acute care services and prescription drug coverage are important coverages for waiver participants.

In 1989, average annual health care costs for waiver participants are running $27,490. Of that cost, hospitalization is averaging $16,990, waiver services and drugs about $6,000, and all other services about $4,500. The average length of stay on the waiver is 4.1 months. The average for foster children is slightly higher, 6.4 months.

New Jersey is expanding ACCAP to include 700 persons in 1990. It will also begin a longitudinal study of 400 participants. Using the waiver program, New Jersey is able to provide medical and supportive services to increasing number of persons with AIDS.

as a testing ground for new services or for new limits on certain services. For example, case management is a service that has been tested in the waiver program. States' use of case management under waivers has given them experience that can be used to inform their selection and use of this strategy as a targeted state plan option.

Testing benefit limitations is another way in which states profit from waiver experience. For example, the number of home health visits may be restricted under the state plan. A waiver provides the opportunity to test the concept of unrestricted visits with limited financial risk. State policymakers can observe the utilization of the expanded benefit in the smaller arena and consider whether Medicaid can afford to offer the benefit expansion to the entire Medicaid population. In this way, waiver programs can be used much like prior authorization programs are used to observe utilization. After a period of prior authorization, a state may move its observation to postpayment review, confident that the service is unlikely to be overutilized or abused. Waiver programs offer similar opportunities to assess utilization and potential abuse.

Eligibility. Applications for participation in the waiver may be made at a local social services office, but the assessment and processing of applications tend to be coordinated by staff specifically assigned to waiver programs. The complex nature of the medical and social needs of waiver children require special understanding of these needs and what the Medicaid program can do to address them. States frequently develop a staff with appropriate medical training and home health and social work experience to assess and plan for these children. Although medical and technical training are important, experience with these children, their families, and the portions

of the Medicaid program that address their needs generally make central review of these cases more efficient.

Another reason for a centralized review process, is that these cases are limited in number and receive services beyond the normal scope of Medicaid. While they utilize the same acute care services as other Medicaid recipients, the additional services they receive set them apart from the rest of the state's Medicaid population.

Moreover, eligibility determinations for waiver children always encompass questions of cost-effectiveness. Children must be considered in the cost-effectiveness test for the waiver in which they participate. Waivers generally designate the annual reimbursement rate for the equivalent institutional level of care as the expenditure ceiling for waiver participants. For example, if the waiver is for children with intermediate care needs and the annual rate at an intermediate care facility is $35,000, then the expenditure ceiling per child is set at $35,000 per year. This number is used in the cost-effectiveness formula as the cost for institutional care. However, most waiver programs are designed to measure cost-effectiveness for the group. A child whose care needs exceed the individual limit may be allowed to continue in the waiver, because the state is confident that savings on other children will compensate for above-average costs on one child. Cost-effectiveness almost always is considered before the child is added to the waiver, because failure to meet overall cost-effectiveness could jeopardize the waiver and the care afforded to all other waiver children.

In determining an individual's cost-effectiveness under the waiver, insurance often is a factor. If a child has private insurance covering institutional care but not home care, he or she may not be added to the waiver. This can occur if private insurance covers the entire costs for institutional care or if it pays an amount that is equal to or more than the Medicaid limit, resulting in no Medicaid payment. If Medicaid pays nothing for the institutional care, then even one Medicaid dollar spent on home care causes the child to fail the cost-effectiveness test. Thus, Medicaid compares its share of the institutional cost—not total institutional cost—with its share of the home care cost. It may be cheaper for Medicaid to leave the child in the hospital.

Part of the long-term solution to this problem is encouraging private insurers to provide community-care benefits or, in specific instances, to convert hospital benefits to home health benefits. Some states' experience with serving disabled children in their own communities has led to changes in private insurance coverage. Maryland's Home Care for Technology Assisted Children waiver produced significant cost savings with improved health outcomes for participating children. After witnessing the state's success with this population, Blue Cross/Blue Shield of Maryland contracted with the Medicaid service provider to develop a program for some of their high-cost beneficiaries. Rhode Island, which started a model waiver for hospital level of care children, detailed coordination with private insurers as one of its waiver program requirements. Now the state will turn to private insurers of its target population to ask for their support in coordinating care for these children, arguing that the failure of the Medicaid waiver would impact negatively on the private insurers. Failure of the waiver could result in reinstitutionalization of the children at full cost to their insurers.

New York's CARE AT HOME Program

Begun in February 1986, fifty physically disabled children under age eighteen currently participate in New York's model waiver program, the "CARE AT HOME Program." To be eligible, children must meet the SSI disability criterion; have been hospitalized or in a skilled nursing facility (SNF) for at least thirty days, or in an intermediate care facility for the developmentally disabled (ICF/DD) for at least 180 days; require the level of care provided in a SNF or ICF/DD; be able to be cared for appropriately in the community and at no greater cost than in an institution; and be ineligible for Medicaid when in the community because of parental income and/or resources.

Of the children currently being served under the waiver, forty-seven came home from hospitals, two from hospital-based SNFs, and one from an ICF/DD. Primary diagnoses for these children include bronchopulmonary dysplasia, congenital heart disease, seizure disorder, spinal cord injury, short bowel syndrome, and cerebral palsy.

The children range from under one year to seventeen years of age. They reside in twenty-one districts throughout the state. Average parental annual income is approximately $38,000 per year.

Services for the group include medical services identified under individual care plans, case management, and respite care. The local social service office arranges home assessments and care plan development and designates case management and respite care providers.

State legislation governing the waiver limits monthly Medicaid spending for these clients to either the SNF or ICF/DD rate for the geographical area in which they reside. For 1989, these expenditure ceilings range from $3,100 per month ($73,200 per year) to $6,400 per month ($76,800 per year). Generally, private duty nursing comprises 75 percent of monthly expenditures.

A 1987 program assessment found that only 20 percent of the children were maintained at home solely by Medicaid. About 80 percent had private insurance or other third-party resources, which covered 49 percent of their home care costs. Home care costs averaged $81,600 annually per child, compared with corresponding institutional costs of approximately $163,500.

In some cases, the average monthly cost exceeded the Medicaid expenditure ceiling, but the availability of third party resources reduced Medicaid's actual expenditures for these children to an amount well within the Medicaid cap. For example, one child's monthly home care budget was $19,567 when the ceiling for his required ICF/DD level of care was $4,258. Third-party resources covered $18,332, so Medicaid expended only $1,235.

Other cases indicate that home care is much less expensive than institutional care. One child could be served at home for only $1,014 per month, whereas in an institution her care would have cost $5,399. Medicaid realized a $4,385 savings even without the presence of third-party payers.

Obviously satisfied with the program, the New York Department of Social Services expanded its waiver to 200 children in 1989. The state also added another model waiver serving 200 hospital level of care children. Thus, New York's commitment to serving chronically ill children continues to grow.

In many ways, waivers have encouraged states to take the lead in financing and coordinating comprehensive home health benefits. Pressures on states to control Medicaid costs, combined with cost containment standards of waivers, have resulted in more children being served in a home setting.

Care Planning and Coordination. Upon development of the plan of care, states, providers, and disabled children and their families must work together to achieve its successful implementation. State experience demonstrates that intensive care coordination is extremely important to the success of waiver programs for disabled children. Effective case management contributes to cost containment, quality assurance, and continuity of care.

Case managers monitor all aspects of a child's home care program. They review the plan elements, consider changes to the plan when the child's health status changes, assist in identifying new providers when there are shortages of providers or

problems with them, access services from other state agencies, and sometimes review claims for consistency with care plan requirements. The case manager is the essential person when a care plan breaks down.

Medicaid and the physician may or may not be informed when a care plan breaks down. Some families become very savvy at working with home health agencies to guarantee that their needs are met or to request a provider change. Others assume the burden of uncovered nursing or home health aide hours without complaining or questioning whether another, better equipped agency can be located. A case manager who knows the child, the family, available community providers, and other state agencies can make the difference in the effectiveness of home care.

Interagency Cooperation. Care coordination often is difficult because numerous providers and public agencies are involved in the implementation of a single care plan. Nearly all waivers require some coordination with other state agencies. For one waiver, health screenings may be administered by the Children with Special Health Needs program, speech therapy and social services supplied by education, and case management provided by community services. Medicaid may determine eligibility and prepare cost reports, but turn over the waiver administration to the mental health department.

Such examples of interagency cooperation are common in waiver program experience. Medicaid agencies' coordination with other agencies to develop comprehensive home care packages is crucial to efficient utilization of state resources for waiver populations. Many TEFRA programs have benefited from and expanded upon interagency efforts used under waivers.

Provider Participation. Continuity of home care has been a problem for many waiver programs due to insufficient numbers of professionals trained to work with medically fragile children. These problems have led states to experiment with various methods for recruiting and contracting nurses, home health aides, and personal care assistants.

Maryland Medicaid's practice of permitting families to advertise for home health nurses was developed in response to shortages of such professionals in its Home Care for Technology Assisted Children waiver program. Registered nurses and licensed practical nurses who have demonstrated skills for working with medically fragile children are recruited by parents through, for example, newspaper advertisements. The nurses become Medicaid providers and then bill the state directly for their services. Parents find and work with nurses they prefer and, in Maryland's case, this has produced the added benefit of reduced costs. The rate for independently contracted nurses is $18.00 per hour, whereas nurses obtained through the home health agency cost $23.40 per hour. Savings are used to support other services in the child's care plan.

Creative strategies for recruiting home health providers at affordable rates are essential as the numbers of disabled children increase. These children often require twenty-four-hour care, and identifying sufficient numbers of trained personnel to provide that care is critical to the continuation of HCBS for disabled children.

Cost-Effectiveness Assurances. While identifying appropriate providers is a problem for waiver programs, burdensome paperwork is by far the most common complaint states have against HCBS waivers as a home care option. Proving cost-effectiveness at the end of a waiver period is one of the most difficult requirements. Cost-effectiveness must be proved by comparing services received in one year with the costs for those services in that same year. This comparison is complicated by two factors. One is that providers have up to one year to submit claims. The second is that Medicaid claims are tracked by date of payment rather than date of service. The administrative burden associated with reconciling these differences in order to develop cost reports is substantial. Generally, states must wait a year until all claims are filed before they attempt the comparison. Proven cost-effectiveness is required for waiver renewal. Thus, states applying for waiver renewals actually prove the effectiveness of the waiver in its second year. This limits the ability to prove effectiveness based on the full waiver experience.

Another problem related to the cost-effectiveness assurance required under waivers is that the state must demonstrate that institutional beds would be available for these waiver participants should they require them due to a change in health status or if the waiver services are no longer available. This aspect of the cost-effectiveness test, commonly referred to as the "cold bed" requirement, is criticized for arbitrarily limiting the number of persons who can be served under the waiver. Thus, unused beds rather than care needs often dictate whether children can be served under the waiver. Many argue that this requirement reinforces and perpetuates Medicaid biases toward institutional care.

Another obstacle to waiver expansion and stability is the renewal process. Renewals are sometimes contingent on a state's agreement to restrain growth in both recipient numbers and waiver expenditures. Moreover, between the time of initial approval and renewal, HCFA's interpretation of what is acceptable under waivers may change. If a state's initial waiver design differs from the newer guidelines, even though there have been no changes in regulations, major revisions in coverage, numbers of participants, or payment may be required in order to obtain a waiver renewal. These factors in the renewal process make state waiver planning and budgeting difficult. They also contribute to uncertain futures for waivers, their populations, and their services.

Despite the uncertainty that surround them and their burdensome administrative requirements, states have used waivers effectively to confront the challenges of providing cost-effective, noninstitutional care to children with complex care needs. Waivers continue to offer states an opportunity to provide services greater both in number and scope than they could afford to provide to their entire Medicaid population. Through developing specialized, coordinated services to targeted groups, states have provided substantial medical and supportive services to increasing numbers of disabled children.

TEFRA State Plan Option

In many ways the program and policy considerations of the TEFRA option are the same as the waiver program. Yet, because the TEFRA option allows access to, and

operates within, states' standard Medicaid programs, additional program issues arise. For those evaluating the option's effectiveness, for those working with the children who gain Medicaid eligibility through this option, and for states considering whether to select this policy option, the TEFRA program presents many challenges.

Foremost, states are able to increase their commitment to disabled children by adding greater numbers to the Medicaid program, and can do so without assuming the burdensome administrative tasks and uncertainty associated with waivers. However, while the TEFRA option provides Medicaid access to more disabled children, it typically offers them fewer services than do waiver programs.

Populations and Services. The TEFRA option feature that allows Medicaid coverage of all qualifying children is considered advantageous by some states. Critical support can be offered to more families with the additional benefit that more children are serviced in the community. The more Medicaid can support children in the home the more dollars are saved, especially over these children's lifetimes.

Other states view the feature of unlimited numbers as disadvantageous, making the option unmanageable and too costly. Their estimates of disabled children who live in the community and who do not receive Medicaid indicate that their Medicaid programs could not support all the children who would qualify for the option if it were selected. Such states have rejected the TEFRA option and in most cases continue to use waivers to care for portions of this population.

While the number of qualifying children is an issue for some states, the services these children will require is problematic for others. Even states willing to consider the increased numbers of Medicaid-eligible children may be reluctant to select the TEFRA option, because the limited nature of home health services under their state plan may preclude assurances that children made eligible through this option can be cared for appropriately at home. States are legally required to provide such assurances. Given a state's fiscal situation, it may be impossible to add services sufficient in quantity and scope to meet the needs of this population, especially since services added to the state plan for this group must be offered to all Medicaid recipients.

Although many states view uncontrolled growth in terms of numbers of children and their service needs as the major obstacle to their selecting the TEFRA option, other states have seen the problems associated with uncontrolled growth somewhat differently or have found ways to control that growth. Some states simply see limited services under their Medicaid program as an advantage in helping control the number of new eligibles; children who cannot be cared for appropriately and adequately at home cannot qualify for Medicaid coverage through this option. Moreover, some states have found methods to restrict access to those services added to benefit this population. For example, Mississippi decided to add physical therapy and speech therapy when it took on the TEFRA option. In order to avoid opening up those services to its entire Medicaid population, the state restricted them to those in the Early Periodic Screening, Diagnosis, and Testing Program. Thus, only children qualify for the new services. Similarly, services can be targeted to recipients based on medical necessity or appropriateness. Wisconsin used this approach when adding respiratory therapy. The service is limited to ventilator-dependent persons. In adding hourly nursing care, Michigan limited the new service to recipients whose medical

condition necessitates the service and who are managed under individualized care plans.

Another factor in controlling TEFRA program growth appears to be the extent to which the program is publicized within the state. States advertising beyond local eligibility offices generally have experienced higher numbers of enrollees than states not utilizing such methods. For example, Massachusetts, Minnesota, and Wisconsin have aggressively advertised their TEFRA option programs through special brochures, public service announcements, and speaking engagements before advocacy groups, and they have larger programs. Broad advertising contributes to increased application by families with children already living at home. A gradual acceleration of program advertisement may lead to steady growth which, in some states, may be critical to program success and avoidance of option repeal.

Brian, A Massachusetts TEFRA Option Child

Brian is a twelve-year-old boy suffering from cerebral palsy, spastic quadriparesis, seizure disorder, mental retardation, and a swallowing disorder. He lives in Massachusetts with his parents and three sisters. His parents' annual income is $42,000.

He receives medical care and is approved for twenty-eight hours per week of nursing services, but currently there is no nurse available during the hours his mother needs assistance. Physical, occupational, and speech therapies are provided twice weekly at Brian's school, which pays for these therapies. Last year Medicaid paid $7,100 in claims for his care. Payments were for physician, hospital outpatient, pharmacy, and home health agency services. Brian is no longer covered by family insurance. When the family changed insurance plans, the new company would not cover him due to his disabilities.

Before Brian's parents found out about the TEFRA option, they were struggling to pay all of his medical expenses and to care for the rest of the family. His mother tried to stretch the family budget, but even so she could not pay many physician and medical supplies bills. She constantly received calls from creditors seeking payment for overdue bills.

In mid-1988, Brian's swallowing problem worsened. He needed gastrostomy surgery to insert a tube for intravenous feeding. His family's insurance company would not pay for the operation, because it classified him as terminal. The public hospital said it would perform the operation, but could not seem to schedule the surgery. The day after Brian's Medicaid card arrived, the public hospital said it could perform the operation that week.

At the time of the operation, Brian weighed twenty-five pounds and could barely move because he was so weak from insufficient nutrition. He also was experiencing serious skin breakdown. Less than a year later, he weighs fifty-five pounds, has fewer infections, is more alert, and is learning to crawl. He is back in school and is beginning to communicate by using switches to answer yes or no. Brian also is expected to be able to eat again soon.

While the TEFRA program does not have the convenient controls of the waiver program in terms of the numbers of eligibles or services, states are developing approaches to manage the growth caused by the TEFRA option. As experience with the program and its growth increases, there will be more knowledge for other states to draw upon in their planning for adoption of the TEFRA option.

Eligibility Processes. The process for determining Medicaid eligibility through the TEFRA option is complicated. States choose various methods for case evaluation and review. Perhaps more frequently than is the case with waiver programs, states use a decentralization or mainstreaming approach to evaluating these children.

For some states, the mainstreaming of these children into the regular Medicaid and social services eligibility process makes sense because once they are approved they receive regular Medicaid services, and their claims data are not required for program renewal. Also, if community-based care is to become the norm, a single eligibility process should accommodate both healthy and disabled children. Alternatively, larger TEFRA program states like Massachusetts, Michigan, and Wisconsin can reasonably assert that the complexity of both these cases and the Medicaid eligibility system necessitates that these cases be evaluated by a few, trained individuals who can shepherd them through the intricacies of SSI and Medicaid eligibility processing (see Appendix D for more information on Massachusetts' program).

Eligibility and Cost-Effectiveness. As with the waiver program, the underlying principle of the TEFRA program is support for cost-effective home care for children meeting the disability criterion. Medicaid's cost for home care should be no more than Medicaid would spend on the child in an institution. This standard constrains program eligibility in at least two significant ways.

First, children requiring hospital level of care who have insurance covering hospital care, but not home care, cannot qualify for Medicaid through the TEFRA option. Similar to the situation under the waiver program, when insurance is paying the entire hospital bill or enough of the bill so as not to trigger Medicaid payment, bringing the child home means that the first Medicaid dollar spent results in failure to meet the cost-effectiveness test. States have numerous examples of children with private insurance coverage for a specified or unlimited number of hospital days, but little or no home care coverage. This usually means that the child must remain institutionalized until the insurance runs out. Costly institutional care continues, and private insurance dollars are exhausted rather than prolonged and maximized.

Insurance coverage generally is a more significant issue under the TEFRA program than under the waiver program because each child's cost-effectiveness is considered individually. TEFRA children cannot benefit from the cushion afforded waiver children, where one child's expenditures may exceed the ceiling because another waiver child may require lower expenditures. Under the TEFRA option, waiting for exhaustion of insurance benefits often is the only solution in cases where states test for cost-effectiveness prior to granting Medicaid eligibility.

Children requiring skilled nursing facility (SNF) or intermediate care facility (ICF) level of care are less likely to experience this Medicaid access constraint, since most insurance policies do not cover these benefits in either the institution or the home. If insurance is not contributing to the child's SNF or ICF care, Medicaid is probably paying most or all of the bill.

Where insurance is problematic, TEFRA program staff in many states are working with private insurers to encourage their support of home care by converting some institutional benefits to home care benefits. In Vermont, the Medicaid planning team coordinates Medicaid and private insurance coverage to assure the participation of all liable third parties. When necessary, the Medicaid agency obtains the assistance of the state insurance commissioner in interpreting insurers' responsibility for home care benefits included in applicable policies. Medicaid program staff in Massachusetts

have found that if insurers permit them to coordinate with the same representative for each case or for all TEFRA option cases, this can save endless hours of like explanation on program requirements and a child's medical history. Moreover, workers have found that if they can work with the same person, they can begin to educate insurance company employees as to how company dollars can be used in a more cost-effective manner and result in healthier children and more satisfied families. While some companies are amenable to this approach and even provide benefits managers for high-cost cases, others do not, and in addition, continue to support institutional benefits over home care coverage.

A few states are attempting to coordinate between private insurance companies and their clients before they become Medicaid recipients. In Minnesota, the Children's Home Health Care Task Force initiated a Medical Technology Assistance Review Panel (MedTARP). Six experts, including a physician, a nurse, the medical director and benefits manager from the insurer or HMO, a technology-assisted consumer or his guardian, and a consumer representative from the insurer's board of directors serve as an interdisciplinary review team. The panel was proposed as an intermediary for technology-dependent individuals up to sixty-five years of age who are disputing with their private insurance companies over home health benefits. It reviews cases after insurance plan grievance procedures are exhausted, but before formal appeal to the state regulatory agency. The panel issues nonbinding recommendations on discharge planning, home health care benefit packages, and/or changes in

Nevada TEFRA Option Program

Beginning its TEFRA program in 1985, Nevada had enrolled five children by the next year. In June of this year, approximately twenty-seven children were being served; of these twelve were mentally retarded, eleven were technology-dependent, and two were ventilator-dependent. As of November, thirty-six children were enrolled, and ten applications were pending.

Initial applications are made in district welfare offices, but the program is operated primarily in the state Medicaid office. Nevada Medicaid periodically convenes a 1902(e)(3) Board, named after the authorizing section of the Social Security Act, to evaluate Medicaid TEFRA applications. The board, whose actual membership varies depending on staff availability, typically is composed of a physician, a nurse specializing in home care, and a home services or disability social worker.

Each case is reviewed by one board member who makes a recommendation to the board on that case. Upon approving a case, the board designates a Medicaid expenditure limit and makes recommendations to the family. A common recommendation is that the family retain their private insurance.

Nevada's emphasis on encouraging families to retain private insurance apparently pays off, because among the program enrollees are some for whom Medicaid makes no medical payments. Between July and September 1989, payments ranged between $25.28 and $18,086. The child costing Medicaid $25.28 had actual expenses that quarter of $4,600. Medicaid expenditures for the other child represented 60 percent of the $30,000 in total care costs. The remaining expenses in each case were covered by private insurance companies. Total program dollars in fiscal 1989 were $150,500.

Nevada Medicaid identified a number of advantages of the TEFRA program, including minimizing the risk that services will be delivered to disabled children in an arbitrary and capricious manner, providing standardized services to all Medicaid recipients regardless of how they became Medicaid-eligible, and providing cost savings to Medicaid. However, Nevada cautions that administration of these cases is often time-consuming.

In addition to the TEFRA program, Nevada offers home care to disabled children through a HCBS waiver that offers case management and habilitation services to the mentally retarded. Another waiver for the physically disabled provides case management and homemaker services.

home care service delivery or reimbursement. MedTARP was initiated because state officials observed that many individuals were having difficulty accessing home care benefits in their private insurance plans. In addition to improving home care for privately insured individuals, it is expected that the panel's intervention will delay or prevent many Medicaid applications.

A second way in which cost-effectiveness constrains Medicaid coverage through the TEFRA option is by limiting access to those requiring an institutional level of care equivalent to the institutional types covered in the state plan. For example, states not covering pediatric SNF cannot use the TEFRA option to bring a child home from that institution. If public policy prohibits payment for pediatric SNF care, Medicaid's cost for a child in that facility is zero. If a child subsequently is brought home and Medicaid contributes one dollar toward that child's care, the cost-effectiveness standard is breached. In addition to affecting the numbers of children eligible in a state, this standard may influence the characteristics of the TEFRA program population within a state. For example, Michigan does not cover pediatric SNF care; most of its children require a hospital level of care, which is an institutional coverage for children in the state. A state's decision to exclude a type of institutional coverage presents a serious obstacle to Medicaid eligibility through the TEFRA program.

The cost-effectiveness test for the TEFRA option presents access problems for some children with private insurance and for other children requiring institutional levels of care not covered by the state's Medicaid program. The latter situation has no obvious solution. These problems are more serious than they are under the HCBS waiver program, because TEFRA cost-effectiveness is judged individually rather than for a group. However, the insurance problem can be alleviated if private insurers are willing to convert institutional benefits to home health benefits. Many Medicaid agencies are working with insurance companies to enlist their support in coverage of comprehensive home health services.

Care Planning and Coordination. Like eligibility processing, systems for care plan development operate in various ways. However, states seem to fall into one of two categories: those that utilize internal state employees and those that rely on external home health providers to develop the care plan.

Some states employ specialized case managers to work with physicians, home health providers, other state agencies, and the family to develop a care plan. Massachusetts and Michigan, for example, consider this approach to be most effective, because state-employed care plan developers are well informed on state programs and procedures and are better equipped to consider maximum Medicaid coverages as they identify care plan requirements. Where needs exceed private insurance and Medicaid coverage, alternative payment and service delivery sources must be specified. For example, home health aide hours beyond the Medicaid limits may be essential. If Medicaid cannot pay for those hours, perhaps another program can offer support. Since care plan developers may have to be creative in piecing together the necessary elements, using well-informed state case managers can be critical to developing appropriate, comprehensive care plans.

States relying on home health providers to work with physicians and families on care plan development report success with this approach, because the providers

are very familiar with home health care and are in close contact with the family over the course of that care. Minnesota relies on experienced home health providers to develop plans for its TEFRA children. Providers develop treatment plans based on medical information supplied by the physician. They proceed based on their training and familiarity with the Medicaid program. If a plan is expected to exceed $1,325 per month, the provider uses state-supplied Home Care Cost Assessment procedures to determine whether a higher expenditure threshold is appropriate. Implementation of the care plan proceeds. Any excessive home care expenditures are found and recouped during the postpayment review of cases (see Appendix E). Vermont has developed a set of protocols to which a provider must agree in order to be designated a technology-dependent high-risk provider. Providers sign protocol agreements requiring them to plan and provide or contract for all necessary medical professionals (see Appendix F).

Especially in states using home health providers as care planners, the issue of care coordination or case management is a closely related one. States using this approach consider it economically efficient and most effective because the home health provider is in the home more frequently than is a case manager and is better informed on the home situation. Furthermore, the provider can be held accountable based both on professional standards of care and on disallowances of claims submitted for excess services.

Critics of this approach argue that home health agencies and medical suppliers coordinate care in ways that are most advantageous to them and that may not necessarily be in the child's best interest. They are more likely to approve extended home health services and to encourage reliance on, rather than independence from, home health professionals. Supporters of this approach argue that these persons are the best care coordinators, because they know both the state systems and provider communities and can be most effective at negotiating both systems to maximize support for the family's needs. Ideally, the case manager becomes a true advocate for the child and the family.

Some TEFRA children have no case managers. The families of such children are essentially on their own to negotiate the maze of home health providers and Medicaid rules. Although some families can meet this challenge successfully, the pressures on many families with disabled children make them less than ideal care coordinators. Care coordination may be an even more important service for the TEFRA child than for the waiver child, because the centralized approach to waiver program management and the limited numbers of children often mean better care coordination for them.

Interagency Cooperation. Another important element of care coordination is interagency cooperation. Fiscal realities and the larger numbers served under the TEFRA option have fostered new levels of cooperation between Medicaid and other agencies, beyond those developed under the waiver program.

Interagency cooperation can assist Medicaid by building on other agencies' expertise with subsets of the disabled population, such as the mentally retarded, developmentally disabled, or mentally ill. The state's MR/DD agency, CSHN program, and mental health divisions each support Medicaid's work with disabled

Melissa, A Michigan TEFRA Option Child

Melissa was born in August 1986, with diagnoses of superior vena cava syndrome, short bowel syndrome, and hydrocephalus. She subsequently developed bronchopulmonary disease (BPD) and severe retinopathy. She requires an apnea monitor and is oxygen dependent due to her BPD. Careful monitoring of fluid levels and weight is critical to her care. For Melissa, any type of infection is accompanied by pronounced respiratory problems.

Melissa's family made several attempts to care for her outside the hospital setting. Each time she was rarely home for more than four or five consecutive days before being rushed back to the hospital in severe respiratory distress. Because her father's job took him away from home for long periods of time, Melissa's mother often had to quickly find someone to accompany her on the seventy-five-mile trip to the hospital, rather than lose precious time in waiting for air ambulance service. These recurring hospitalizations were very stressful for all family members, including her older sister. Melissa's physician was presented with a dilemma: while he believed in home-based care, he was not sure it was feasible for her. The hospital utilization committee also was questioning Melissa's "revolving door" care plan.

In June 1988, a referral was made to the Specialized Home Care Program (SHCP) for "specialized" assistance with discharge planning, home care coordination, and payment for in-home services. Melissa's physician was skeptical that any program could make a difference. However, with SHCP supports, Melissa was home eight weeks without a rehospitalization. By then, everyone involved in her care was optimistic that home care could really work for her. This first "successful" home stay was particularly remarkable because her mother delivered a healthy new baby boy, who came home about the same time as Melissa!

Now, sixteen months later, Melissa continues to do well at home. While she still requires intermittent hospitalizations for respiratory infection, those hospitalizations are fewer in number and are for shorter lengths of stay. Protocols have been developed for adjusting oxygen levels based on pulse oximeter readings, and for adjusting lasix based on her weight, which is taken twice daily. Eleven hours per day of nursing care currently are authorized.

Melissa has flourished at home. She is beginning to talk and to feed herself and she crawls and pulls herself to a standing position. Well oriented to her environment, she can find toys where she last played with them although she has no vision. This ability to remember where things are demonstrates she may not be as intellectually impaired as first thought. She now attends a school-based program three half-days a week and receives early intervention services at home.

Both Melissa's health status and the community-based service system have stabilized to the extent that the "specialized" care management offered by the SHCP is no longer needed. However, the program continues to fund her home care, to conduct quality assurance reviews, and to provide support for managed care by the local health department. Compared with hospitalization, Melissa's home care results in a $32,396 savings of public funds.

While Melissa's parents are now divorced, her mother, sister, and brother are taking pleasure in Melissa's advances and are benefitting from a stable service system with few hospitalizations. The lives of Melissa and her family have been enriched by the opportunity for care at home.

children while improving care for their specific populations. For example, in exchange for expertise and time in case managing these children, Medicaid can offer federally match-enhanced dollars to assisting agencies. Medicaid funds, other state dollars, and MR/DD or CSHN resources can be integrated to address a range of medical and social service needs.

Many Medicaid agencies have made such arrangements with other state agencies. Michigan's Medicaid agency turned over its entire TEFRA program to the CSHN program. Medicaid considered that agency's familiarity with the population and its needs superior and better suited to coordinating care for the disabled children. Minnesota Medicaid is making a trade with its Services for Children with Handicaps (SCH). In exchange for Medicaid's processing of claims, SCH provides case management for TEFRA families. Recognizing that SCH was better equipped to provide case

management for these children, Medicaid adopted a strategy that maximizes state energies and dollars expended in these cases.

Also important for interagency cooperation is the Education for the Handicapped Act's mandate to provide free education and support to developmentally delayed children between the ages of three and five by school year 1991-92, and the accompanying discretionary program to provide similar support to children up to age three. There are lead agencies in all states, and Interagency Coordinating Councils (ICCs) in most, which are beginning to address the medical, educational, and family support needs of developmentally delayed children. The success of these programs will depend on effective coordination between Medicaid and other state programs. In many states, Medicaid will be expected to be the major funder of necessary services. Medicaid agencies will want to be involved in the ICC process. ICCs' decisions on defining the population they will address are likely to affect Medicaid directly through greater identification of children and their Medicaid needs. Medicaid agencies also may want to be involved as ICCs and state agencies proceed in implementing support services for chronically ill children.

The TEFRA program has increased interagency cooperation, although the often substantial numbers added to Medicaid dictate the need for continued effort in this regard. Such cooperation will help ensure the efficient utilization of state dollars in the provision of well-coordinated care for families with disabled children.

Provider Participation. The shortage of obstetricians has been publicized extensively. Moreover, state responses to NGA's survey indicate that shortages exist among all types of health care providers. Inadequate numbers of appropriately trained, equipped, and available providers exist in selected areas of most states. Reports of physician and home health agency shortages in rural areas are common, but so are shortages of registered nurses, home health aides, and various types of therapists. In addition, urban areas report shortages in all categories. Furthermore, urban areas sometimes have the additional problem of unsafe neighborhoods, so that even if there are providers within reasonable distances from a child's home, they may be unwilling to conduct a home visit.

Registered nurses, whether privately contracted or hired through home health agencies, often are in short supply. While nurses may prefer working in the home setting, they often left the institutional setting to work regular, daytime hours. Families and agencies have many problems finding nurses for evening and night hours. When nurses are unavailable, families inevitably are the backup. Constant turnover means additional work for the family in acquainting new nurses with their child and in communicating their expectations of how the nurse/family relationship should proceed.

Nurses are not the only provider managed by the family in their home. Home health or nurses aides play a significant role, and shortages and turnover also occur among this group. The scenario is the same. When trained personnel are unavailable, the family takes over.

Contributing to the short supply of home health aides are low Medicaid reimbursement rates for these activities. The increased need for these workers has increased awareness of the low rates, but not all states have been able to raise them.

Some states have attempted to address the problem by paying a higher rate for a semi-skilled home health aide and a lower rate for a less-skilled personal care attendant. Moreover, some states are allowing families to hire and manage their own aides and attendants, including neighbors or relatives. However,, such programs usually must be funded through 100 percent state monies, since Medicaid reimburses only Medicaid-certified providers.

Arkansas uses Maternal and Child Health grant funds to train specialized babysitters in providing respite care for families with medically fragile children. Trainees are provided meals and free transportation to a conference center. They spend three days in training sessions and, on the fourth day, actually care for such children. The program has increased the number of respite workers available to meet the needs of families entitled to two weeks of respite care per year. When trained, the respite babysitters earn $5.00 per hour. Families who do not qualify for state payment of this care pay between $.25 per hour and $1.25 per hour for babysitting based upon a sliding fee scale.

Other efforts to work around or resolve provider problems address the physician shortage. Nebraska experienced problems with local physicians who were reluctant to sign on as attending physicians for medically fragile children in their community. Physicians considered their knowledge of relevant medical conditions limited and they feared the liability they would incur by agreeing to sponsor the child. To address these fears, state and hospital personnel from the primary Omaha hospital treating these children link local physicians with specially trained pediatricians who can provide guidance and reassurance in times of crises. Also, the hospital provides some training to increase physicians' understanding of these children's needs.

While some dilemmas remain vis-a-vis the recruitment and training of home health professionals, states are initiating innovative approaches to resolve these problems and to improve the quality and coordination of home care for disabled children.

In deciding whether to adopt the TEFRA option, a state must consider how many additional children will become eligible and what existing state plan services will support their home care. A state also should consider the cost of serving additional children in the community as well as current and future institutional costs that may be necessary for those children. Finally, a state must assess its capacity to overcome the barriers in planning and coordinating community-based care.

While planning home care can be challenging, states selecting the TEFRA option have the opportunity to extend Medicaid coverage to more disabled children. They develop different approaches to managing the program, reviewing applications, and coordinating the home care. Some states use specialized staff and case managers to review and monitor cases. Others integrate applications into existing Medicaid systems and use social service caseworkers or home health providers as care coordinators.

Regardless of the administrative procedures selected, states confront some common difficulties. Developing care plans generally requires working with private

insurers, other state agencies, and providers in order to assemble resources and provide payment for all necessary services. After developing such care plans, states often have difficulty identifying sufficient numbers of appropriate providers to serve children's needs due to provider shortages occurring in both urban and rural areas. Providing consistent quality care is a formidable task in many home care cases.

The TEFRA and HCBS waivers options share many planning, implementation, and analysis challenges. For both options, states must consider numerous issues, including eligibility expansions, care coordination, provider availability and reimbursement, case review, program administration, and cost. How states evaluate each of these factors varies depending on their Medicaid program and disabled population. States' conclusions on these issues inform their decisions as to the best strategy for serving disabled children in the community.

State experience demonstrates that each option has advantages and that there are good reasons for maintaining both. The TEFRA program covers more disabled children, while the waiver program affords states the opportunity to develop innovative care programs for specific subpopulations. States may use one option or both in developing community care systems. However, the complexion of these programs may change as this population grows and as several related public policy issues continue to evolve, especially those related to financing.

4. Future Considerations in Home Care

The current challenges in caring for disabled children are substantial. Yet, a look to the future quickly indicates that there are many unresolved issues surrounding this population and that current problems in providing for their care are likely to become more complex. Growing numbers of disabled children, identifying providers to care for such children, and deciding who should pay for their care are just a few of the myriad dilemmas.

Population Growth

The numbers of disabled children continue to increase. The National Health Interview Survey, which revealed a 3 percent growth in this population between 1960 and 1984, does not account for advances in medical technology, the spread of AIDS, or increasing rates of chemical addiction among childbearing women in the last five years. Surely, these factors have already contributed to additional growth.

As increasing numbers of health-compromised children survive, decisions on quality of life must be addressed. Society, the health care industry, and individuals must continue to formulate positions on what constitutes an adequate quality of life, before advanced medical technology is enlisted to support continuation of life. Such decisions should relate to society's level of commitment to families sent home with neonates on life support. These families must pay the extraordinary medical, social, psychological, and financial costs associated with their children's intensive health care needs.

Public policymaking also must address the fact that as health care costs increase and available public health care dollars decrease, paying high health care costs for one child necessarily deprives others of coverage. How the public dollar should be utilized for children's health care and to what extent their care should be supported by private dollars will have to be addressed in the debate.

For Medicaid, all of these issues are relevant: how to address the growing numbers of disabled children, how to define quality of life, and how to allocate Medicaid dollars among healthy and disabled children. The continuing health care debate on these children is especially critical for Medicaid because Congress, advocates, and some portions of the private sector desire to broaden the scope of disabled children supported by the public sector. Almost certainly, increased public sector financial support of disabled children will be primarily Medicaid's responsibility.

Alternative Care Settings

Currently, the major impetus for Medicaid to move beyond its institutional bias and to increase home care options for disabled children is cost containment. The push for home care has been advantageous for some children and their caregivers, but problematic for others.

Early efforts to bring children home from hospitals or institutions usually were initiated by parents eager to bring their child home to a supportive environment where medical and emotional needs could be addressed. As hospitals move to push patients out because Medicaid inpatient hospital reimbursements do not adequately cover their costs, as Medicaid programs are pressured to save more dollars, and as adequate institutional placements diminish in number, children are more frequently sent home to families incapable of meeting the challenge of caring for a disabled child. Families who care for disabled children report increased family stress, lost income due to increased caregiving hours and reduced employment hours, lost career opportunities, and less time to spend with other family members. Even families eager to bring their child home report significant stress related to these issues. It is easy to imagine how such stresses impact single-parent families and families less interested or less capable of caring for a medically fragile child.

Family-centered, community-based, coordinated care has been the motto of those supporting noninstitutional care for disabled children. But these criteria do not have to translate home care. A noninstitutional, home-like care program may be a foster care or group home living arrangement rather than the nuclear family's home. Efforts to move children out of institutions and into the community must not presume that every parent is capable of caring for their child. For children whose families cannot care for them, for those whose families require respite from care demands, and for older children requiring independent living situations, alternative community-based settings are needed. Public policymaking must consider and plan for further development of noninstitutional care settings that can accommodate disabled children's needs.

Provider Participation

Expansion of community-based care settings already is being compromised by insufficient numbers of trained providers who are willing to work with disabled children. States' efforts to identify and appropriately reimburse home health providers are beginning to address current provider shortages. However, existing and projected shortages are more serious and ubiquitous than can be addressed by these initiatives.

If the nursing home reform law requirements designed to increase nurse aide training opportunities and status are successful, lessons from that experience may be applied to home health aides and respite care workers. Broader, more coordinated efforts to train such individuals may encourage more to become home providers, thereby reducing current provider shortages and enabling families to better carry their share of the caregiving load.

Problems of supply and payment of appropriate home health professionals also are tied to certification requirements and standards of care. Home health in most

states is based on Medicare conditions of participation for home health agencies, and standards on administration of home health care were developed specifically for the elderly population. These standards often present obstacles in meeting the home health needs of disabled children. In addition, the standards sometimes contribute to Medicaid agencies requiring skilled professionals to supply services that semi-skilled individuals can be trained to provide.

Another factor contributing to home health provider shortages is reimbursement. As demands for higher reimbursement by home health providers increase, both public and private payers will have difficulty meeting costs for home health costs. For Medicaid, higher home health rates present the recurring problem that substantial spending on one group of recipients limits the funds available for other groups. Moreover, higher home health rates will make it more difficult to justify the cost-effectiveness of home care. For private insurers, increased home health costs may result in more beneficiaries using up their total benefit package, which could increase insurers' liability and reduce profits.

While reimbursement for home health services is an important issue, Medicaid programs and private payers must be careful about embracing increased reimbursement as the entire answer to provider shortages. As demonstrated by several studies on physician and obstetrician reimbursement, increased payment is not the answer to Medicaid physician participation. Furthermore, higher rates do not always influence professionals' decisions to pursue certain medical specialties such as those relevant to caring for disabled children. In addition to payment, physicians consider malpractice risks, clientele, personal preference for medical specialties, and the work schedules required in specialties. When considering incentives to encourage professionals to pursue home health practices, policymakers must examine a range of issues in conjunction with payment policies.

Shortages of appropriately trained home health providers who are willing to work with disabled children present significant challenges to Medicaid agencies planning home care. Although home health reimbursement is an issue, recruitment, training, and certification strategies also must be considered as answers are sought to provider supply problems.

Public Financing Role

The underlying rationale for the public sector's commitment to disabled children's home care is the cost containment strategy encouraging Medicaid to cover lower-cost home care options. However, when cost containment, rather than improved or reasonably maintained health status, is the starting point for developing a disabled child's home care package, conflicts inevitably arise.

The presence of private health care insurance can pervert the process of planning a child's home care. If a family has full hospital coverage, it can be forced to exhaust hospital benefits, which really means exhausting its entire insurance coverage, before a child can become Medicaid-eligible. Such circumstances leave the family exposed for 100 percent of its future health care needs. Families who cannot afford health care costs may turn to Medicaid for coverage of all family members.

Moreover, when a child's private coverage is exhausted, Medicaid immediately becomes responsible for all of his or her hospitalization costs. Given that disabled children are hospitalized twice as often as healthy children and are hospitalized for periods that are twice as long (Newacheck 1987), the fiscal responsibility for Medicaid is substantial. When Medicaid programs are able to bring children home and to use their scarce funds to support lower-cost care home health expenditures, private hospitalization dollars can be conserved for return hospital visits, which usually involve higher-cost acute care services. Further, these resources can be used to support the needs of additional children.

Situations requiring exhaustion of private insurance benefits before Medicaid coverage can begin provide incentives to uninsure medically fragile children. Some families are advised to remove the child from the family health insurance plan, so Medicaid can assume coverage and home care can begin. Public policies that encourage families to drop insurance contribute to the public sector becoming further burdened with high-cost cases. As the public sector takes on more of the burden, the private sector's responsibility for these children decreases.

Incentives to exhaust or drop insurance run counter to Medicaid reimbursement principles that allow states to pay premiums to maintain private health insurance. Medicaid dollars spent on insurance premiums are federally matched precisely so private health insurance coverage may be extended and Medicaid expenditures on individuals who have access to private insurance can be minimized.

Finally, state and federal policymakers must continue objective assessment as to whether partial support of home care for disabled children, together with social support for their families, avoids substantial investments for those children later in their lives. These children have many years ahead of them, and the severity of their illnesses often precludes self-sufficiency. When family members tire from the strain of providing and paying for medical care, or when parents become too old to care for their children, costly institutions frequently become the answer. Institutional care is nearly always paid for entirely by Medicaid. If most of these children access Medicaid at some point, it is in Medicaid's interest that they be as healthy and independent as possible. Relatively healthy and independent children will be less expensive and easier to provide for than will children who have lived their entire lives in institutional settings.

Clearly, more consistent policy on the use of public health dollars is necessary to resolve current conflicts between cost containment and comprehensive home care for disabled children. Careful study and policy development regarding the role of Medicaid expenditures also could result in substantial future savings.

Private Financing Role

The question of how to spend public dollars is intimately related to how private health care dollars are being used. While some private insurers already are covering some costs for these children, the number of insurers actively participating in home care coverage remains limited.

Some insurers have studied Medicaid case management and cost containment strategies and have adopted versions for their own high-cost clientele. A few insurers have modified their benefits packages to include home care, often referred to as "individual benefits management." According to a 1984 survey by the Health Insurance Association of America, Lincoln National Corporation and Aetna Life and Casualty have added individual benefits management to all of their plans. Approximately half of the Blue Cross/Blue Shield plans have added this benefit, and Prudential has added it to 20 percent of its plans (Newacheck 1987).

However, for the most part, private insurers remain reluctant to provide comprehensive home health coverage for disabled children. Their plans contain biases for institutional care and against home care. When plans do cover home health, they often are limited to higher-cost services and providers, which encourages more rapid spenddown of total benefit dollars. Many plans cover only skilled nursing in the home. When a beneficiary requires home health aides, but not registered nurses, insurance benefits end. Persons who can live at home are forced back into institutions or onto Medicaid. Whether as a result of paying for high-cost home health services or paying for institutional care, the $1 million benefit cap on most insurance plans is quickly exhausted by disabled children.

State survey responses indicate that, in addition to indemnity health insurance coverage, health maintenance organizations occasionally present obstacles to providing appropriate, comprehensive home care. Although HMOs generally would be considered as quite willing to support lower-cost home care, there have been instances of HMOs sending children home from institutions so they can reclassify them as custodial care cases and curtail expenditures on them. Like other private sector health care providers, HMOs may respond like this in complicated cases, because overall increases in health care costs are compromising their ability to address even the acute care needs of their enrollees.

Another aspect of private sector responsibility for these children involves determining to what extent families of disabled children should contribute to their care. Should a percentage of the family's gross income be assessed and, if so, what percentage? Is 20 percent, which is the current average percentage families with disabled children spend, appropriate? Or should families pay a higher percentage? Federal law allows spouses of institutionalized adults to retain designated levels of income and resources in order to avoid poverty. Should families with disabled children be afforded the same privilege? Is a required family contribution the appropriate policy response to the problem of limited public dollars for health care, or would such a policy foster negative incentives, for example, encouraging families to disown or institutionalize their children? These questions are complex and involve new challenges for public health policymakers.

Issues relating to the appropriate role of the private sector in supporting home care for disabled children are complicated. Once that role is decided upon, the steps necessary to encourage private insurer action in the desired direction also will be necessary. Ultimately, the private and public sector roles must be considered together if suitable policy ends are to be achieved.

Resolution of public and private sector roles in financing community-based care and development of a range of care settings for increasing numbers of disabled children are among the difficult issues continuing to challenge those designing programs. How policymakers respond will influence the further development and structure of states' community-based care programs for disabled children.

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Appendix A

Home- and Community-Based Services Waiver
Cost-Effectiveness Criteria

Home- and Community-Based Waiver Cost-Effectiveness Formula

$$\frac{(A \times B)+(A' \times B')+(C \times D)+(C' \times D')+(H \times I)}{F + H} \quad _ \quad \frac{(F \times G)+(H \times I)+(F' \times G')}{F + H}$$

KEY:

A = unduplicated number of recipients in the institutions with waiver

B = cost of A

A' = unduplicated number of recipients in the institution receiving acute care with the waiver

B' = cost of A'

C = unduplicated waiver recipients receiving waivered services

D = cost of C

C' = unduplicated waiver recipients receiving acute care services and other noninstitutional long-term care services provided under the state plan with the waiver

D' = cost of C'

F = unduplicated number of recipients in the institution without the waiver

G = cost of F

F' = unduplicated number of recipients in the institution receiving acute care services and other noninstitutional care services provided under the state plan without the waiver

G' = cost of F'

H = unduplicated recipients receiving Medicaid services in the community

I = cost of H

SOURCE: Health Care Financing Administration's State Medicaid Manual, 1989.

Appendix B

Part H Lead Agencies under the Education for the Handicapped Act (P.L. 99-457)

PART H LEAD AGENCIES UNDER THE EDUCATION FOR THE HANDICAPPED ACT (PL 99-457)

STATE	LEAD AGENCY
Alabama	Education/Crippled Children's Services (CCS)
Alaska	Health and Social Services
Arizona	Economic Security/Developmental Disabilities (DD)
Arkansas	Human Services/DD
California	Developmental Services
Colorado	Education
Connecticut	Education
Delaware	Education
District of Columbia	Human Services
Florida	Education
Georgia	Human Resources/Mental Health-Mental Retardation-Substance Abuse (MH-MR-SA)
Hawaii	Health/CCS
Idaho	Health and Welfare/DD
Illinois	Education
Indiana	Mental Health
Iowa	Education
Kansas	Health and Environment
Kentucky	Human Resources/MH-MR
Louisiana	Education
Maine	Interdepartmental Committee
Maryland	Governor's Office of Children and Youth
Massachusetts	Public Health
Michigan	Education
Minnesota	Education
Mississippi	Health
Missouri	Education
Montana	Social and Rehabilitation Services/DD
Nebraska	Education
Nevada	Human Resources
New Hampshire	Education
New Jersey	Education
New Mexico	Health and Environment/DD
New York	Health
North Carolina	Human Resources/MH-MR-SA
North Dakota	Human Services
Ohio	Health
Oklahoma	Education
Oregon	Mental Health/DD
Pennsylvania	Public Welfare
Rhode Island	Interagency Coordinating Council
South Carolina	Health and Environmental Control
South Dakota	Education
Tennessee	Education
Texas	Interagency Council
Utah	Health
Vermont	Education
Virginia	MH/MR/SA
Washington	Social and Health Services
West Virginia	Health and Social Services
Wyoming	Health

SOURCE: National Early Childhood Technical Assistance System, August 1989.

Appendix C

Home- and Community-Based Services Waivers, May 1989

TABLE II - 1

HOME- AND COMMUNITY-BASED WAIVERS
(waivers in effect as of 5/1/89) (1)

STATE	EFF. DATE (2)	POPU-LATION	CASE MNGT.	HOME-MAKER	HM. HLTH. AIDE	PERS. CARE	ADULT DAY	HABILI-TATION	RESPITE CARE	OTHER (3)	# BEING SERVED (4)	FED/ST $1,000s	WAIVER YEAR
AL	10/1/82	MR/DD						X			1,592	7,832	'87
	10/4/84	A/D	X	X		X	X	X	X	X	3,808	10,211	'87
AR	1/1/89	MR/DD	X					X	X	T	----	----	----
CA	7/1/83	A/D	X				X		X	T	3,329	7,119	'87
	7/1/82	MR/DD		X	X	X	X	X	X	T	----	----	----
	7/1/83	A/D	X		X					H	----	----	----
	7/1/87	A/D			X					X	----	----	----
	1/1/89	AIDS/ARC	X	X						H	----	----	----
CO	7/1/82	A/D	X	X		X	X		X	T,H	3,281	8,408	'86
	10/1/82	MR/DD	X			X		X	X	X	1,580	26,800	'87
CT	10/1/82	A/D	X	X			X		X	T,X	----	----	----
	10/1/87	M/R	X					X			----	----	----
DE	7/1/83	MR/DD	X					X	X	X	91	1,042	'86
	7/1/86	A/D	X	X			X		X	X	----	----	----
FL	4/1/82	A/D	X	X		X	X		X	T	7,991	5,338	'87
	4/1/82	MR/DD	X						X	T	18	12,750	'87
	12/1/86	A/D	X	X			X		X	X	132	92	'86
	7/1/85	A/D	X	X	X	X	X		X	H,X	632	2,362	'87
	8/1/86	A/D	X			X				X	46	81	'86
GA	10/1/81	A/D	X	X	X	X			X	X	5,499	9,598	'86
	7/1/88	MR/DD		X	X	X		X	X	X	----	----	----
HI	7/1/83	MR/DD	X				X	X	X		57	564	'86
	8/1/83	A/D	X	X		X			X		45	321	'86
	8/15/83	A/D	X	X		X	X	X	X	T,X	306	2,495	'87
	4/1/88	AIDS/ARC	X			X		X	X	T	----	----	----
	1/1/89	MR/DD	X			X	X		X	X	----	----	----
ID	1/1/84	A/D,MR/DD				X					----	----	----
IL	12/1/83	MR/DD	X					X	X		----	----	----
	7/1/83	A/D		X		X	X			X	5,748	8,202	'86
	7/1/83	A/D	X	X			X			X	11,605	22,837	'86
IN	9/1/84	A/D	X	X					X		69	59	'87
KS	3/22/82	A/D, MR/DD	X	X	X		X	X	X	X	1,510	3,641	'87
KY	4/1/83	MR/DD	X	X	X	X	X	X	X	X	637	10,927	'86
	7/1/83	A/D	X	X		X	X		X	H	286	307	'87
LA	1/6/82	A/D					X				----	----	----

SOURCE: NATIONAL GOVERNORS' ASSOCIATION

TABLE II - 1 (CONT.)

HOME- AND COMMUNITY-BASED WAIVERS
(waivers in effect as of 5/1/89)

STATE	EFF. DATE (2)	POPU-LATION	CASE MNGT.	HOME-MAKER	HM. HLTH. AIDE	PERS. CARE	ADULT DAY	HABILI-TATION	RESPITE CARE	OTHER (3)	# BEING SERVED (4)	FED/ST $1,000s	WAIVER YEAR
ME	7/1/83	MR/DD	X					X	X	T	----	----	----
	5/1/85	A	X	X		X	X			T,X	902	3,033	'87
	7/1/86	A/D	X			X					26	38	'86
MD	2/3/84	MR/DD	X					X		T	662	13,515	'87
	1/1/88	C/D	X								----	----	----
MA	1/1/84	A/D	X	X					X	X	----	----	----
	1/1/84	MR/DD	X			X	X		X	T	----	----	----
MI	10/1/87	MR/DD						X		X	----	----	----
MN	7/23/82	A	X	X	X	X	X		X	X	----	----	----
	7/1/84	MR/DD	X	X				X	X	X	991	13,169	'87
	10/1/87	D	X	X		X	X	X	X		----	----	----
MS	11/1/86	A/D, MR/DD	X	X			X		X	X	----	----	----
MO	4/22/82	A/D	X	X					X		3,519	3,213	'87
	1/1/84	A/D	X	X					X	T	34	686	'87
	7/1/88	MR						X	X	T	----	----	----
MT	7/1/83	A/D	X	X		X	X	X	X	X	494	3,576	'86
	7/1/83	MR/DD	X	X		X	X	X	X	X	210	2,146	'87
NE	10/1/87	MR/DD	X					X		X	----	----	----
	8/1/88	A/D							X	T	----	----	----
NV	7/1/82	MR/DD	X					X			135	1,379	'87
	7/1/87	A/D	X	X			X		X	X	----	----	----
NH	9/1/83	MR/DD	X			X	X	X		X	551	13,519	'86
	7/1/87	A/D	X	X	X		X		X	X	247	713	'87
NJ	10/1/82	MR/DD	X			X		X	X		----	----	----
	10/1/83	A/D	X	X					X	T	2,197	8,543	'86
	3/1/87	AIDS/ARC	X			X				X	----	----	----
NM	7/1/83	A/D	X	X			X		X	T	438	2,218	'87
	7/1/87	AIDS/ARC	X	X		X	X			X	----	----	----
	8/1/84 (5)	C/D	X	X		X			X	X	28	125	'88
	7/1/83	MR/DD	X	X		X		X	X	X	117	307	'87
NY	12/2/82	A/D							X	T, X	4,453	1,915	'86
NC	7/1/82	A/D	X	X			X		X	X	1,799	8,284	'87
	7/1/83	MR/DD	X	X		X		X	X	X	306	3,036	'87
ND	4/1/83	MR/DD	X	X	X	X	X	X	X		741	5,320	'86
	10/1/83	A/D	X	X	X	X	X		X	T	342	933	'86

SOURCE: NATIONAL GOVERNORS' ASSOCIATION

TABLE II - 1 (CONT.)

HOME- AND COMMUNITY-BASED WAIVERS
(waivers in effect as of 5/1/89)

STATE	EFF. DATE (2)	POPU-LATION	CASE MNGT.	HOME-MAKER	HM. HLTH. AIDE	PERS. CARE	ADULT DAY	HABILI-TATION	RESPITE CARE	OTHER (3)	# BEING SERVED (4)	FED/ST $1,000s	WAIVER YEAR
OH	7/1/84	A/D	X	X	X	X	X		X	X	613	1,960	'87
	1/1/88	AIDS/ARC	X	X		X	X		X	T	----	----	----
OK	1/1/85	MR		X				X	X	X	58	221	'87
OR (6)	12/23/81	MR/DD		X				X	X	T, H	669	6,744	'87
	12/23/81	A/D								H	----	----	----
PA	10/1/86	MR	X				X	X	X	T, H	----	----	----
RI	1/1/82	A/D	X	X			X			T, H	603	9,002	'87
	7/1/83	MR/DD	X	X					X	H	----	----	----
	7/1/88	A/D	X	X			X			H	----	----	----
SC	10/1/84	A/D	X			X			X	X	5,485	9,750	'87
	8/1/88	AIDS/ARC	X			X				X	----	----	----
SD	6/1/82	MR/DD	X					X		X	622	6,150	'87
	10/1/88	A		X			X			X	----	----	----
TN	6/1/86	A/D	X			X			X	H	----	----	----
	7/1/86	MR/DD	X					X	X	X	----	----	----
TX	9/1/85	MR/DD	X	X				X	X	X	157	1,824	'87
	6/29/88	C/D							X	X	----	----	----
UT	7/1/87	MR/DD						X	X		----	----	----
VT	4/1/82	MR/DD	X				X	X	X		205	4,630	'87
	4/1/82	MI	X				X	X	X		77	1,790	'87
	7/1/87	A/D	X				X		X	X	----	----	----
VA	6/18/82	A/D				X					3,715	13,741	'87
WA	1/1/83	A/D	X			X				X	----	----	----
	12/1/83	MR/DD	X					X	X	X	980	12,643	'86
WV	7/1/82	MR/DD	X					X	X	T	'87	777	'87
	7/1/82	A/D	X	X						X	360	1,204	'87
WI	1/1/87	A/D	X			X	X	X	X	T, H, X	----	----	----
	10/6/83	MR/DD	X					X	X	H	233	4,079	'86
	8/1/87	MR/DD	X					X	X	H	----	----	----

KEY:

1. BASED ON HEALTH CARE FINANCING ADMINISTRATION'S OFFICE OF COVERAGE POLICY 5/1/89 WAIVER LIST.
2. REFLECTS THE EFFECTIVE DATE OF THE FIRST WAIVER DEVELOPED FOR THIS GROUP.
3. IN THE "OTHER" CATEGORY, T = TRANSPORTATION, H = MINOR HOME MODIFICATION, AND X = OTHER.
4. THE NUMBER OF INDIVIDUALS SERVED AND EXPENDITURES FOR THE WAIVER YEAR INDICATED ARE BASED ON THE HEALTH CARE FINANCING ADMINISTRATION'S BUREAU OF QUALITY CONTROL'S LISTING OF HCFA-372 REPORTS ACCEPTED IN FISCAL YEAR 1988.
5. THIS WAIVER BEGAN AS A MODEL HOME- AND COMMUNITY-BASED WAIVER.
6. OREGON HAS A WAIVER UNDER SECTION 1915(d) AUTHORITY, EFFECTIVE 10/1/88. IT IS INCLUDED HERE BECAUSE THE EXPENDITURE AND RECIPIENT DATA ARE FOR THEIR EARLIER SECTION 1915(c) WAIVER.
7. THIS WAIVER REPLACED A MODEL WAIVER FOR THIS GROUP .

SOURCE: NATIONAL GOVERNORS' ASSOCIATION

TABLE II - 2

HOME- AND COMMUNITY-BASED MODEL WAIVERS
(waivers in effect as of 5/1/89)

STATE	EFF. DATE (2)	POPU-LATION	CASE MNGT.	HOME-MAKER	HML HLTH. AIDE	PERS. CARE	ADULT DAY	HABILI-TATION	RESPITE CARE	OTHER (3)	# BEING SERVED (4)	FED/ST $1,000s	WAIVER YEAR
CA	7/1/87	A/D			X					H	----	----	----
CT	10/1/83	MR/DD; D	X							X	----	----	----
GA	9/1/84	C/D	X							X	3	93	87
	6/26/86	C/D	X							X	----	----	----
ID	10/1/83	A/D	X			X			X	T, H	----	----	----
IL	7/1/85	AIDS C/D			X				X	X	----	----	----
IA	8/1/84	C/D; MR/DD		X	X	X	X		X	X	36	71	87
KY	8/1/87	C/D								X	----	----	----
	10/5/87	VENT.DEP.								X	----	----	----
MD	1/1/85	C/D	X							X	----	----	----
MI	10/1/85	MR/DD							X	X	1	5	'85
MN	4/1/85	D	X	X					X	H	18	852	'87
MS	1/13/83	C/D	X								----	----	----
NV	10/1/89	D	X	X							----	----	----
NJ	9/1/83	B/D	X								----	----	----
	4/1/85	B/D	X							X	53	185	'87
	4/1/86	B/D	X							X	43	941	'86
NY	12/1/85	C/D	X						X		7	3	'85
NC	7/1/83	C/D AIDS	X						X	X	----	----	----
OH	10/1/83	MR/DD	X	X		X		X	X	T	40	653	'86
	10/1/83	MR/DD	X	X		X		X	X	T, H	25	300	'86
PA	7/1/87	D	X							X	----	----	----
RI	4/1/86	D	X			X				X	----	----	----
SC	1/1/87	C/D							X	X	----	----	----
TN	7/1/86	MR/DD	X			X				H	----	----	----
VA	1/31/88	C/D							X	X	----	----	----
WA	12/1/87	D	X					X	X	X	----	----	----

KEY:

1. BASED ON HEALTH CARE FINANCING ADMINISTRATION'S OFFICE OF COVERAGE POLICY 5/1/89 WAIVER LIST.
2. REFLECTS THE EFFECTIVE DATE OF THE FIRST WAIVER DEVELOPED FOR THIS GROUP.
3. IN THE "OTHER" CATEGORY, T = TRANSPORTATION, H = MINOR HOME MODIFICATION, AND X = OTHER.
4. THE NUMBER OF INDIVIDUALS SERVED AND EXPENDITURES FOR THE WAIVER YEAR INDICATED ARE BASED ON THE HEALTH CARE FINANCING ADMINISTRATION'S BUREAU OF QUALITY CONTROL'S LISTING OF HCFA-372 REPORTS ACCEPTED IN FISCAL YEAR 1988.

SOURCE NATIONAL GOVERNORS' ASSOCIATION

Appendix D

Massachusetts Department of Public Welfare's Kaileign Mulligan (TEFRA) Home Care For Disabled Children Program Application Packet

Instructions For Completing
The Kaileigh Mulligan Home Care For Disabled Children Program
Application Packet

All the information that you provide in this application is confidential. The only people who can see this information are Department of Public Welfare personnel and their agents. This information will only be used to determine eligibility and identify the services your child will need at home.

Initial Program Application

- Answer all questions to the best of your ability. Please use a pencil or black ink. Your responses will help program staff to make disability and "level of care" determinations, to develop an Individual Service Plan, and to estimate the annual cost of home care for your child.

- Complete a release form for *each* provider involved in the care of your child (e.g., physicians, hospitals, clinics, home health agencies). We will send these forms to your child's medical providers with a request for medical records and other necessary information.

- Include the most recent physician report and medical record for your child, as well as a copy of the most recent developmental assessment performed by your child's physician (or by the qualified professional prescribed by your child's physician to perform the assessment). We will use this information in our initial assessment of your child's medical condition.

  Note: If your child is presently hospitalized or a resident of a pediatric nursing home, you need submit only the most recent medical records from that facility with the program application. Also, be sure to attach a copy of your child's Social Security Administration disability determination, if your child is an SSI recipient.

Please send all the application materials to the following address:

Kaileigh Mulligan Home Care for Disabled Children Program
Medical Division/Department of Public Welfare
600 Washington Street, Boston, MA 02111

Program Redetermination

- Please omit the questions noted in the application. Answer all other questions to the best of your ability using a pencil or black pen.

- Send the completed form to either your Public Health Case Manager or to the Kaileigh Mulligan Program staff at the address noted above.

(In addition to having you complete this application, we will be requesting updated medical report(s) directly from one of your child's physicians. Additional reports may be requested on a case-by-case basis.)

Questions

If you have any questions about the requested information, call the Kaileigh Mulligan Program staff at 617–348–5510 (in Greater Boston) or 1-800-222-2719 (outside Greater Boston).

HCDC-7 (Rev. 11/88)
22-007-1188-80

The Kaileigh Mulligan Home Care for Disabled Children Application

Child's Name _____ Date of Birth _____

Child's Social Security Number _____

Parent(s) Name(s) _____

Address _____

City _____ State _____ ZIP _____

Telephone Number/s: Home (___) _____

Work (___) _____ (Father) Work (___) _____ (Mother)

If parents have separate addresses and telephone numbers, please list those of both parents.

_____

Family members in home: Adults _____
Other children and their ages _____

A. **General Information** (At redetermination, please omit questions 2, 3, 4 and 6.)

1. Briefly describe in your own words your child's major disabling condition/s, when (month/year) it first became a problem, and include any secondary physical/mental impairments.

   _____

   _____

   _____

   _____

2. Is this disability the result of an accident? Yes ☐ No ☐
   If yes, date of accident _____

3. a. Does your family and/or your child currently receive Medicaid? Yes ☐ No ☐

   If yes, under which program?

   1. ☐ Supplemental Security Income (SSI)
   2. ☐ Aid to Families with Dependent Children (AFDC)
   3. ☐ Medicaid
   4. ☐ Other

b. If recently denied or terminated from SSI or Medicaid, give date, reason, and Medicaid number.

Date	Reason	Medicaid Number

4. Does your child receive: a. ☐ Social Security b. ☐ Medicare?

5. Is your child currently receiving services from any of the following public agencies? Yes ☐ No ☐
If yes, what services?
   a. ☐ Department of Social Services _____
   b. ☐ Department of Education (Chapter 766) _____
   c. ☐ Department of Public Health _____
   d. ☐ Department of Mental Health _____
   e. ☐ Massachusetts Commission for the Blind _____
   f. ☐ Other _____

6. Does your child have a Department of Public Health Case Manager? Yes ☐ No ☐
If yes, please list name, regional office location and telephone number.

_____

7. a. Does your child attend school? Yes ☐ No ☐
If yes: Public ☐ Private ☐ Special Needs Children Only ☐

Name of School _____

Address _____

Telephone Number ( ) _____

Name of primary teacher _____

b. Is your child currently enrolled in a Department of Public Health Early Intervention Program?

Yes ☐ No ☐ If yes, please indicate name and address of the program.

_____

_____

c. Does your child miss school on a fairly regular basis? Yes ☐ No ☐
If yes, how often? _____

d. If not attending school, does your child receive home services through the school system?

Yes ☐ No ☐ If yes, please explain below.

_____

_____

8. Is your child's developmental (functional) level age-appropriate? Yes ☐ No ☐
If no, what is the developmental age? _____

B. Physicians

1. Please list the name, address, and telephone number of the primary physician (pediatrician, family practitioner, general practitioner) who cares for your child.

   Name _____

   Address _____

   Telephone Number ( ) _____

2. How often does the primary care physician see your child? _____

3. Has your child had any of the following tests in the last year?

Test	Check Appropriate Block or Blocks		If "Yes" List	
	Yes	No	Where Done	When Done
Electrocardiogram	☐	☐		
Chest X-Ray	☐	☐		
Other X-Ray (name body part here)	☐	☐		
Breathing Tests	☐	☐		
Blood Tests	☐	☐		
Other (specify)	☐	☐		

4. Please list other physicians who participate in the care of your child.

Name/Address	Specialty	Telephone	Frequency Seen
		( )	
		( )	
		( )	
		( )	
		( )	
		( )	

C. Institutional Care (At redetermination, include only hospitalizations within the past year.)

1. Please list names, addresses, and dates of admissions and discharges for hospitals where your child has been an inpatient.

   _____

   _____

   _____

2. Please list number and types of outpatient visits, in the past year.

_____

_____

3. If a hospital visit is scheduled within the next 12 months, please note where, when, and why.

_____

_____

D. Activities of Daily Living

1. Movement: Please note which apply to your child.

	Independent	With Assistance (1, 2 person(s), device?)	Is Not Able
Walk			
Crawl			
Sit Up			
Turn			

2. Sight, Hearing, Speech

a. Please note which apply to your child.

	Good	Fair	Poor	None
Sight				
Hearing				
Speech				

b. Is your child considered legally blind? Yes ☐ No ☐ If yes, is he or she registered with the Massachusetts Commission for the Blind (MCB)? Yes ☐ No ☐

Name/Telephone Number of Case Worker_____

3. General Hygiene

a. Please note which apply to your child.

	Independent	With Assistance	Is Not Able
Bathing			
Dressing			

4. Feeding

a. Please indicate below how your child is able to feed and note how often and for how long.

	Feedings Per Day	Minutes Per Feeding
Oral		
Gastrostomy Tube		
Nasogastric		

b. Please describe any special diet or formula for your child. _____

_____

c. Does your child receive parenteral (intravenous) nutrition? If so, please describe solutions and frequency.

_____

_____

5. Toileting

a. Please note which apply to your child.

	Yes	No	Other (i.e., catheter, colostomy)
Bladder Control			
Bowel Control			

b. If your child uses diapers, how many per day? _____

E. Medical Condition

1. Respiratory

a. Does your child require any of the following respiratory aids?

1. ☐ Suction (bulb ☐ or machine ☐) Frequency _____

2. ☐ Oxygen ☐ Humidification

Number of hours per day _____ liter flow _____

3. ☐ Chest Therapy Times per day _____

2. Dental

a. How often does your child see a dentist?_____

b. Does your child have extraordinary dental problems? Yes ☐ No ☐ If yes, describe.

_____

F. Home Nursing Care

1. Does your child receive skilled nursing care at home? Yes ☐ No ☐
If yes, indicate the type below:

a. ☐ intermittent skilled nursing visits through a home health agency

b. ☐ private duty nursing services (continuous skilled nursing of two hours or longer)

☐ delivered by a home health agency

☐ delivered by an independent nurse provider

2. If yes to "1" above, please note the hours and type on the weekly schedule below.

	MON.	TUES.	WED.	THURS.	FRI.	SAT.	SUN.
Registered Nurse							
Licensed Practical Nurse							
Home Health Aide							

3. Name/telephone number of agency and/or individual providing the care.

_____

4. Are there additional nursing services that you feel your child would benefit from?

_____

_____

_____

5. Briefly describe the skilled nursing treatment(s) or procedure(s) required.

_____

_____

_____

G. Therapies

1. Does your child receive therapeutic services? Yes ☐ No ☐
   If yes, please note below where and what types.

Type of Therapy	# of Visits Per Week at Home	# of Visits Per Week at School	Provider Agency
Physical			
Occupational			
Speech			
Respiratory			
Other			

H. Other Health Insurance

1. Do you have family health insurance? Yes ☐ No ☐
   a. If yes, is the child covered? Yes ☐ No ☐
   b. If yes:
   Name of insurance_____
   Child's Identification Number _____ Group Number _____
   Employer/Group Name_____
   Insurance Company Telephone Number/Area Code_____
   Insurance Company Address_____

   c. If applicable, total amount of insurance coverage available to your child.

   _____
   Approximate amount remaining _____
   Deductibles _____ Limitations _____

   d. Does the insurance cover the costs of the following and, if so, how much?

   1. Home Nursing Care _____
   2. Physical Therapy _____
   3. Occupational Therapy _____
   4. Speech Therapy _____
   5. Physicians _____
   6. Medications _____
   7. Equipment _____

I. Medications

1. Please list all medications your child takes on a regular basis.

Medication Name	Dose	Frequency	Comments

2. Please list all medications your child takes only "as needed."

Medication Name	Dose	Frequency	Comments

J. **Equipment/Supplies** (At redetermination, please list only those changes from the previous year.)

1. For all items used in your child's care, please check whether purchased or rented and indicate the amount of the item and how often it is used.

Item	Purchase	Rental	Amount and How Often Used			
			Per Year	Per Month	Per Week	Per Day
Ventilator						
Generator						
Ambu Bag						
Suction Machine						
Oxygen Compresser						
Oxygen Tanks						
Apnea Monitor						
Cardiac Monitor						
Nebulizer						
I.V. Pump/Pole						
Wheelchair						
Hospital Bed						
Prone Stander						
Feeding Pump/Pole						
Walker						
Body Jacket						
Braces						
Splints						
Orthopedic Shoes						
Shoe Lifts						
Tracheostomy Tubes						
Gastrostomy Tubes						
Feeding Bags/Tubing						
I.V. Tubing						
Nasogastric (feeding) Tubes						
Syringes						
Formula						
Intravenous Fluids						

2. Dressing supplies (please specify type and amount or frequency used)

_____

_____

_____

K. Other Information

1. Please include any other information about your child's care and/or costs of that care which would be helpful to know in considering your application for Medicaid for your child.

_____

_____

_____

2. Name and telephone number of person completing this application and relationship to child (e.g., parent).

_____

3. Names and telephone numbers of any people helping parent or guardian complete the application.

_____

_____

_____

4. I understand that the information contained in this application will be reviewed by staff from the Department of Public Welfare and its agents for the purpose of determining my child's eligibility for the Kaileigh Mulligan Home Care for Disabled Children Program.

_____
Signature of Parent or Guardian

_____
Date

Appendix E

Minnesota Department of Human Services' Home Care Cost Assessment Instructions

The Minnesota Department of Human Services requires a Home Care Cost Assessment (HCCA) when the cost of medical assistance for nurse visits; home health aide visits; personal care services, including personal care supervision; and private duty nursing will be more than $1,324 for more than two consecutive months. Services can be started by the home care provider in any amount that is medically necessary, before the HCCA is completed. A HCCA is not required when an individual needs home care services in excess of $1,325 per month if expected medical assistance reimbursement for these services will be reduced to under $1,325 by the start of the third month.

Instructions for Use of Worksheet to Estimate Monthly Cost of Medical Assistance Home Care

This estimate should be done for each MA recipient receiving services from your agency, and should become part of the individual's health records.

If the recipient is receiving MA home care services from additional providers, it will be necessary to interview the recipient to determine the extent of services provided by other agencies.

A. For individuals beginning MA home care after January 1, 1988:

1. Complete each of the three columns

2. If the Grand Total is less than $1325 per month, proceed with services.

3. If the Grand Total exceeds $1325, begin needed services and contact the county preadmission screening (PAS) unit (see attached directory) for a Home Care Cost Assessment (HCCA). The cost of services during the interim may exceed $1325 for up to 2 months.

4. Once you receive notice of the monthly limit on MA home care for the individual, you may not exceed that limit without prior authorization from the Department of Human Services.

B. For individuals who received MA home care before to January 1, 1988:

1. Determine the level of home care the individual was receiving in December, 1987. This level (units of service) was "grandfathered in" under Minnesota Rules 9505.0295. This means that, unless care needs actually decrease, the individual is entitled to that level of care, even if it exceeds $1325 per month.

2. If the individual needs additional services beyond those in place in December, 1987, follow the instructions in A.

C. If you cannot safely provide the needed care under the limit authorized by the HCCA, the supervising RN should contact Lynda Adams at 612/296-1551 for information regarding the prior authorization requirements.

Worksheet to Estimate Monthly Cost of Medical Assistance Home Care

Client _____

MA-ID Number _____

Estimate for month of _____

MA Home Care Service	Frequency per Month	Cost per Unit	Total Cost per Month
Nurse Visit from Home Health Agency	_____ Visits*	_____	_____
Home Health Aide Visit from Agency	_____ Visits*	_____	_____
Personal Care Services	_____ Hours	_____	_____
Personal Care Supervision - RN	_____ Hours	_____	_____
Private Duty Nurse - RN	_____ Hours	_____	_____
Private Duty Nurse - LPN	_____ Hours	_____	_____
		Grand Total	_____

* Limited to 1 visit per day

Date of Estimate _____

Provider _____

Commonly Used MA Reimbursable Home Care Costs

Nurse Visit from Home Health Agency	$48.82/visit
Home Health Aide Visit from Home Health Agency	37.45/visit
Personal Care Assistance Services:	
a. from PCA directly enrolled with MA	6.64/hour
b. from PCA employed by PCA Provider Organization	10.42/hour
c. from PCA under contract with PCA Provider Organization	9.90/hour
PCA Supervision visit by RN working for PCA Provider Organization	4.59/15 min.
RN Private Duty Nursing:	
a. RN directly enrolled with MA	13.70/hour
b. RN working for a Home Health Agency which is a Private Duty Nursing Service Provider:	
1. providing services for a recipient who is ventilator dependent	22.85/hour
2. providing services for a recipient who is not ventilator dependent	20.31/hour
LPN Private Duty Nursing:	
a. LPN directly enrolled with MA	10.27/hour
b. LPN working for a Home Health Agency which is a Private Duty Nursing Provider:	
1. providing services for a recipient who is ventilator dependent	18.06/hour
2. providing services for a recipient who is not ventilator dependent	15.52/hour

Appendix F

Vermont Department of Social Welfare Provider Agreement for Technology-Dependent High-Risk Medicaid Clients

PROVIDER AGREEMENT
FOR
TECHNOLOGY-DEPENDENT
HIGH-RISK MEDICAID CLIENTS

This Agreement is for the statewide provision of physician prescribed pulmonary services, infusion therapies, apnea programs, and such services as are made possible by future technological advances in home care. Further, this Agreement applies only to services rendered to children under the age of eighteen years, or to people of any age who require, or who are likely to require, more than one of the above therapeutic modalities.

DUTIES OF THE PARTIES TO THIS AGREEMENT:

The Provider, by signing this Agreement, agrees to the following provisions in addition to those included in the standard Medicaid Provider Agreement.

The Provider will:

1. Supply such durable medical equipment and related supplies and supportive nursing services as required to adequately serve the needs of all Vermont Medicaid, technology-dependent clients located within the State of Vermont. If the provision of these products and services is impossible in any case, for any reason, the Provider shall notify the Medicaid Division as soon as practicable, and in no case, no later than one working day. In such an eventuality, Provider shall provide such products and services as soon as possible.

2. Coordinate, where necessary, with other third party payors to assure continuity of services and payment when payors in addition to Vermont Medicaid are involved.

3. Designate and have available during regular business hours, a liaison for the purposes of communication with the Medicaid Division regarding services provided under this Agreement. Such person shall respond to the inquiries and reasonable requests of the Medicaid Division and its clients served under this Agreement.

4. Provide clinical and administrative emergency consultation services twenty-four hours a day, seven days a week.

5. Provide to its professional and paraprofessional staff, training and education necessary to maintain program standards in the provision of services under this Agreement. Expenses of such training and education to be borne entirely by the Provider.

6. Provide client education materials and consultation to assure that the client understands and is able to use the equipment and services provided under this Agreement.

7. Provide support through its clinical nurse specialists, clinical managers and administrators, for biweekly monitoring and supervision of the job performance of both business and professional staff. It is understood that this includes assistance in the coordination of the provision of necessary and/or desirable services available in the community and funded by sources other than Vermont Medicaid.

8. Provide supportive services rendered only by Registered Nurses, Licensed Practical Nurses, Respiratory Therapists, and other Registered Nurses with High-Tech specialists. All such services shall be rendered in accordance with the American Nurses' Association's Standard of Practice, and the nursing standards established by JCAHO, both of which are hereby incorporated in this Agreement by reference.

9. Provide to the Medicaid Division such documentation as shall be required for client care rendered under this Agreement. Such documentation shall be on the basis of, but not limited to, reimbursement, service quality assurance monitoring, business management productivity, efficiency, and quality control monitoring.

10. Except in those cases where the patient is covered by other health insurance, bill the Vermont Medicaid Program for all services provided under this Agreement. Supportive services shall be billed biweekly.

11. Consult with the patient's physician prior to altering the plan of care if such a change requires medical authorization. The Medicaid Division shall be notified by the Provider of any change in the plan of care which would affect Medicaid clients, or result in any corporate issues of responsibility or liability.

12. Maintain client service records within the State of Vermont in accordance with standards set forth by the Joint Commission on Accreditation of Health care Organizations (JCAHO), and shall furnish to the Medicaid Division on request a copy of the Provider's corporate policies and procedures, as well as a copy of any agreements with other providers associated with the provision of services under this agreement. The JCAHO standard are hereby incorporated by reference.

13. Supply equipment, solutions and supplies in accordance with State and federal laws and in accordance with manufacturer's and JCAHO quality assurance procedures.

14. Maintain the confidentiality of any Medicaid eligibility information with which it is entrusted.

15. Agree to provide services jointly with other service providers only after prior approval has been given by the State, and only on the condition that any such providers agree to abide by both the standard Provider Agreement for Medicaid, and by the applicable sections of this Agreement.

16. Provide stand by equipment in the home of any Medicaid patient when the unit is essential to the short-term life and health of the patient.

17. Provide equipment in the hospital prior to discharge for trial use and training when appropriate.

18. Perform a home assessment prior to the patient's discharge from a hospital, or prior to transfer to this provider.

19. Provide loaner units if the originally rented equipment is taken out of the client's home to be repaired. If such equipment was purchased, any replacement equipment will be provided in accordance with the manufacturer's warranty.

20. On the request of the State, provide to the State, copies of any pre-discharge assessment and other pertinent health information such as discharge summaries, copies of physician's orders, treatment plans, and insurance/reimbursement information.

21. When necessary, notify local essential services prior to the client's discharge. Such local services include, but are not limited to, fire departments, power companies and rescue squads.

22. Maintain, with insurance companies licensed to do business in Vermont, professional liability insurance sufficient in amount and space and shall, upon request, provide the Medicaid Division a certification of such coverage.

23. Participate in care conferences for clients and potential clients to determine appropriateness of providing services and determining initial care plans.

24. Participate in regular client care conferences to review the status of clients being cared for under this Agreement.

25. Indemnify, defend, and save harmless the State and its officers and employees from liability and any claims, suits, judgements, and damages arising as a result of the Provider's performance of the obligations under this Agreement. The parties agree that the Provider, and any agents and employees of the Provider, shall act in an independent capacity and not as officers, agents, or employees of the State.

The State of Vermont, Department of Social Welfare, Medicaid Division, agrees to perform the following functions and duties.

The State will:

1. Pay all claims covered by this Agreement within an average of 30 days of the date of receipt by our fiscal agent, provided that the claims are properly made out and are submitted for eligible clients and for services covered by the Medicaid Program.

2. Make such payment at negotiated rates in effect on the dates services are rendered. Any potential changes to these rates may be proposed by either party at least 30 days in advance, and shall be subject to negotiation.

3. Inform all interested parties of the existence of this Agreement and enroll as high-tech care providers any applicant that can fulfill the duties and qualifications stated or implied by this Agreement.

4. Furnish the Provider with pertinent Medicaid Program regulations, rules and eligibility information.

5. Provide timely prior authorization for those services and products for which such authorization is required.

6. Assure timely response to questions from the Provider.

7. Inform the Provider liaison person of potential clients within two working days from the time the State is first informed.

8. Assist in the establishment of, and participate in, all discharge planning conferences involving potential or actual Medicaid clients.

9. Assist the Provider in the implementation and operation of this Agreement.

10. Furnish the Provider with forms for billing and, whenever possible, notify the Provider of prior approval or denial of Medicaid coverage prior to the provision of Provider services to Medicaid clients.

11. Designate and have available during regular business hours, a liaison person for the purpose of communicating with the Provider regarding program services provided under this Agreement. In special circumstances, provision will be made for communication after regular business hours and during holidays and weekends.

GENERAL PROVISIONS:

1. This Agreement and any addenda shall remain in effect for one year from the date of signature by the State.

2. This Agreement may be cancelled by either party upon 30 day's written notice to the other.

3. In the event of cancellation, each party shall do everything possible to minimize the negative effects of such cancellation on clients, the Provider, and the State.

4. This Agreement may not be assigned by either party to any other individual or legal entity.

5. This Agreement shall be governed and interpreted in accordance with the laws of the United States, the State of Vermont, and the regulations and rules of the Department of Health and Human Services and the Department of Social Welfare.

6. One or more waivers of any term or condition of this Agreement by either party shall not be construed as a waiver of a subsequent breach of the same term or condition. If any provision of this Agreement is held to be invalid or unenforceable, all other provisions will nevertheless continue in full force, and the provision found to be unenforceable shall be reformed to reflect the intentions of the parties.

Signed: _____ Signed: _____

For: _____ For: _____
Provider Department of Social Welfare

Date: _____ Date: _____

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